EXAMINING THE EXPERIENCE OF A MOTHER WITH MULTI-DISABLED CHILDREN

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ABSTRACT

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We live together in society that is composed of individuals who have normal development and individuals who have some developmental delays or disabilities. Therefore, it is important to know and understand what disability is and how it affects the lives of the family members individually also a mother and family as whole. O'Connor (2002) indicates that being a parent of a child who has a developmental delay is a challenge for the parents. This qualitative, mother-focused study examines the experiences of a mother who is rearing multi-disabled children consisting of mental disabilities, a hearing impairment and physical disabilities; and the effects of having more than one child with multi-disability on mother's psychological well-being. Another objective of the study is to explore how a mother copes with this issue in a family setting and the kind of coping strategies the mother uses to manage the difficulties. Case study design was conducted with the mother of multi-disabled children. Qualitative in-depth interviews are conducted with the mother, and information was gathered in the areas of daily stress, coping, family reactions and well-being. Family Systems Theory provides the theoretical framework of the study. The experience, reaction and communication of the mother with both her disabled children and other family members are examined with the light of the family systems theory in order to understand the interrelation among the family members.

Keywords: Family System Theory, Multi-disabled children, Coping of mother

ÖZ

ÇOKLU ENGELLİ ÇOCUKLARA SAHİP ANNENİN DENEYİMLERİNİN İNCELENMESİ

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Bizler normal gelişim gösteren ve gelişsel geriliği veya yetersizliği olan bireylerin olduğu bir toplumda birlikte yaşıyoruz. Bundan dolayı engelin ne olduğunu anlamak, bir annenin aynı zamanda bir ailenin bu engelleden nasıl etkilendiğini bilmek önemlidir**.** O'Connor (2002) gelişimsel geriliği olan bir çocuğa sahip ebeveyn için bunun bir zorluk olduğunu belirtmektedir. Bu niteliksel, anne merkezli çalışma bir annenin çoklu engele sahip çocuklarını büyütme deneyimini; zeka geriliği, işitme engeli ve fiziksel engelden oluşan çoklu engele sahip birden fazla çocuğa sahip olmanın anne üzerindeki etkilerini araştırmaktadır. Çalışmanın bir diğer amacı ise bir annenin aile içerisinde bu durumla nasıl başa çıktığını, bu güçlükleri idare etmek için ne tür başa çıkma yöntemleri kullandığını incelemektir. Anne ile niteliksel ayrıntılı görüşmeler yapılmış, günlük stress, başa çıkma, aile tepkileri ve durumu ile ilgi bilgi toplanmıştır. Aile sistemleri teorisi bu çalışma için kuramsal temel oluşturmaktadır. Annenin, engelli çocukları ve diğer aile bireyleri ile olan deneyim, reaksiyon ve iletişimi aile sistemleri theorisi ışığında daha yakından incelenmiştir.

Keywords: Aile Sistemleri Teorisi, Çoklu engelli çocuklar, Annenin başa çıkması

To my faithful mother, thank you for standing by me thought thick and thin. To my best friend, Omer, your personal steadfastness and reassurance, during my study permitted me to reach this place in my life.

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CHAPTER I

INTRODUCTION

Having a baby or a young child with special needs can be traumatic in many ways. When parents find out that their child has a disability or a chronic illness, they live a life which is full of hard tasks, and confusion in decisions. They may communicate with a great number of people in order to understand the disability of their child or children and try to find a solution for this unexpected situation. Moreover, in the early period of the diagnosis of their children's disability, families may have a feeling of loneliness and isolation. At this time, they are in need of information, assistance, and support from the outside world (Bowe, 2004).

Family is the context within which the most direct and intimate relationships take place. It is very important to support the needs of each family member. As a result of this support, support to the disabled child will be provided earlier. In addition to this there are some issues that are expected from parents to provide for their disabled children (Bowe, 2004). These are; to supply a safe and secure environment in which disabled children can develop their full potential, to pass on culture, for example how we behave, aspects of history, languages, and pass on norms and values (Bowe, 2004).

As professionals if we are to consider the individual and sometimes special needs of each of the children with whom we work with, we should understand their differing backgrounds in order to assess the "whole child" (Wall, 2003). In fact, it is significant to recognize and respect family differences. Parents who are bringing up disabled children go through some challenging experiences that can have additional positive and/or negative effects on individuals. Parents of children with special needs may have different perspectives on development, learning, opportunities and expectations for the future for their children, themselves and the family as a whole (Wall, 2003).

Furthermore, family is a system and this system internally and externally is influenced with presence of a disabled child. This event brings a requirement of reassessment of family functions (Dyson 1989; Gallimore, Weisner, Kaufman, 1989; Koller, Richardson & Katz, 1992; Cohen, Friedrich & Jaworski, 1994; Heaman 1995 as cited in Taanila, Syrjala, Kokkonen & Jarvelin, 2002). For example, Perryman (2005) stated that disabled children are in need of special and sensitive care, and protection. In order to provide effective intervention, parents should monitor their child's condition carefully. They have to provide educational, financial, and medical support. Perryman (2005) indicated that these parents, face with the reality of their child's diagnosis. Moreover, the life that parent planned for their children have changed because they were expecting a healthy child, however, their child is disabled. The expectations, future plans and goals of the parents of disabled children is different from the families who have healthy children. This can start a complex and difficult mourning process that is different for every parent.

O'Connor (2002) states that being a parent of child who has a developmental delay is a challenge for parents. He says that children are likely to be dependent for a longer period. Moreover, parents should provide the demands of their disabled child across the child's lifespan which require emotionally and economically different support from typically developing children (as cited in Woolfson & Grant 2006).

Russell (2003) discussed the importance of investigating and providing the needs of parents of disabled children. Furthermore, he argued that understanding parents of disabled children's expectations is a process that can support parents' understanding of their child and the implications of their disability and can improve the relationships that develop with professionals involved in their child's education and care (Russell 2003).

In a previous study by Douma, Dekker, and Koot (2006), it is found out that parents of children and adolescents with both intellectual disabilities and psychopathology often experience high levels of parenting stress. It is stated that most parents needed some support. Especially they need others to listen to them frankly, and they need counseling in order to gain information about the disability of their children. Douma, Dekker, and Koot (2006) also indicated that parents do not know where and how to find support or may want to solve the problems themselves at first (Douma, Dekker & Koot, 2006).

Besides the parental affect in the family of disabled child, the mother has a particularly significant effect in the family unit. Personality traits of the mothers of disabled and nondisabled children were studied by Roskom (2005). This study identified a relation between the kind of the disability and mother's cognition and behavior in that the mothers with mentally handicapped children showed less positive behaviors than the mothers of children who were sensorially handicapped.

Furthermore, the mothers with mentally handicapped children had a more strict and ruled-based relation with their children than the mothers of sensorially handicapped children (Roskam, 2005).

Nachshen, and Minnes's (2005) findings showed that parents of children with developmental disabilities reported more child behavior problems, more stress, less wellbeing and more social support than parents of children without developmental disabilities.

Although a considerable amount of literature demonstrates the negative effect of having disabled child, there are some studies which reveal the optimistic, hopeful and positive sides of having a disabled child. In a study conducted by Kearney and Griffin (2001), the experiences of parents who have children with significant developmental disability were examined. Findings of the study demonstrated that although the parents experienced much suffer because their children were born with a disability, they had a difficult life and experienced sadness; they also talked about hope, love, strength and joy.

In the present research, experience and coping efforts of a mother with children with multi-disabilities in family system is studied. The effect of multi-disabled children on the family unit is examined especially from the perspective of the mother. The interaction and relationships of the family members among each others in terms of a disability within the family system, and the coping strategies they use, are also examined in the study.

The chapters are organized as follows: Chapter II begins with a general introduction on disability, and continues with a thorough literature review on multi-disabled children, family systems theory, multi-disability in family system theory, and a review of the research on many variables relating to children with disabilities, their parents, siblings and families in relation to family system. There is a description of family systems theory and its usefulness as a framework for studying families, as well.

Chapter III, on the other hand, describes the method used in this research. This includes the case, research design, and collection of data. This chapter also discusses how the themes emerged: perspective on parenting a child with special needs, perspectives on multi-disability, parental acceptance of special needs, family impact, effects on siblings, care giving decisions, family needs, stress and coping. This chapter ends with an analysis of data.

Chapter IV provides the results that were obtained and their relationship to the research questions.

Chapter V discusses the implications of the obtained results, limitations of the study and suggestions for future research.

1.1. The Purpose of the Study

The purpose of this study is to examine the experiences of a mother rearing multi-disabled children, and the effects of having more than one child with multi-disabilities including mental disabilities, hearing impairment and physical disabilities on the mother's psychological well-being. This study also aims to explore how a mother copes with this issue in a family setting and what kind of coping strategies the mother use to manage difficulties. In this in-depth qualitative study, audio-taped interviews were conducted to explore the expectations of the mother during pregnancy and her feelings after childbirth, her children's early years, diagnosis, and her current thoughts and feelings about mothering children with multi-disabilities. This study attempts to answer the following questions:

1. How does having more than one child with multi-disabilities including mental disabilities hearing impairment and physical disabilities affect the mother's psychological well-being in family and social context?
2. What are the mother's perceptions and feelings about having children with multi-disabilities?
3. How does the mother accept her multi-disabled children?
4. To what extent does the mother accept her children's disability?
5. What kind of coping strategies did the mother use to manage difficulties?

1.2. Statement of the Problem

Special children and their families are exposed to the vulnerabilities within the society and policy. These children and their families need special care and concern. In fact, all individuals are equal irrespective of their ethnicity, native language, religion and race in a social and democratic government. I have realized that there are several factors such as ignorance and withdrawal which affect disabled people and their family in the society. Among the disabled individuals and their families, the ones who have been affected from this ignorance and withdrawal are mostly the mothers. In fact, most of the responsibility and load has been especially left on the mother within the family (Benn & McColl, 2004; Traustadottir 1991). Mothers are supposed to take care of not only their disabled children, but also the rest of family members like healthy children, husband, a grand mother and grand father. Also, they are supposed to participate in the education of both their disabled and healthy children. Furthermore, there is lack of care and importance given to the mothers' psychological well-being. They might be in a need of psychological help or treatment (Oelofsen & Richardson, 2006; Ozgun & Honig, 2005). However, this very important part of mother's health is usually ignored by her family and the society. This may cause severe problems. Because the mother is not psychologically well, she can help neither her disabled children nor healthy ones. She cannot shoulder the responsibilities which are expected from her such as duties like being an appropriate mother and a satisfying wife. This is really a very difficult and painful task for her.

I have been working in the field of special education for approximately five years. I have had experience both with disabled children including various handicaps and their families, especially with their mothers. What came out from my experiences was that mothers encounter enormous amounts of stress while rearing and dealing with their disabled children and other family members.

First of all, with this study I would like to highlight the overload of responsibilities of the mother to the society and people who deal with this issue.

Secondly, I would like to emphasize the importance of participation of the mother towards her disabled children' education. The more the mother and her whole family encourage and support the education of their disabled children, the more efficiency the children will gain. As a consequence of this success, both disabled children and their family become happy and comfortable. Their pessimistic point of views about their disabled child and life in general will change to be optimistic.

In order to involve the mother and the total family into the education process of their disabled child or children, it is important to understand, and solve the problems of the mother and analyze the coping strategies the mother uses. In all, it is not possible to provide a proper education for the disabled children without considering the participation of mothers.

Another reason why I am dealing with this issue is because having more than one child with disability and especially having multi-disabled children is a rare case. This situation raised my interest and concern to this topic. In light of all the above reasons, I have preferred to study this valuable topic within a research design.

1.3. Significance of the Study

There is a broad literature about families of disabled children, which examine the factors such as parental stressor, effect of disability on family dynamics, difficulties of rearing a child with disabilities, stress in comparison to the normal children’s families, contribution of social support centers to the disabled families.. Most of this research has documented the effects of the disabled child on the family system. However, there are few studies, which examine the mother as a whole and deeply in terms of the nature of her experiences and coping efforts she makes in this struggling process within the family. Therefore, this study is significant because it extends our understanding of what multi-disability is and how it affects the life of a mother.

This study contributes to the literature from several perspectives. First of all it allows us a look into the life of the mother whose daily routines, relationships, expectations, feelings and every domain of life are deeply affected by her children's handicaps. This research highlights the emotional and psychological phases of the mother while rearing two children with multi-disabilities. Much research in Turkey (Şahin, 2006; Ahmetoğlu, Canarslan, Vatansever, & Kutlu, 2005; Sunal, & Çam, 2005; İçöz, & Baran, 2002) has been conducted on this issue; however, this study will bring profound information about the phases and the acceptance process of the parents with multi-disabled children. There are several studies (Ahmetoğlu & Aral, 2005; Uğuz, Toros, İnanç, & Çolakkadıoğlu, 2004; Özşenol, Işıkhan, Ünay, Aydın, Akın, & Gökçay, 2003; Özşenol, Ünay, Aydın, Akın, & Gökçay, 2002) conducted on disabled children and various professional perspectives explain the challenges and rewards of providing care and support to disabled children. However, few of them give information about the parents who try to explain and describe the disability of their children, their inner perspective, the intrinsic difficulties involved while rearing their disabled children. This study unlike previous research will provide in-depth understanding of rearing practices and experience of having multi-disabled children from the view point of the mother.

1.4. Conceptual Definitions

Impairment: This term is explained as the functional limitation within the individual caused by physical, mental or sensory defect. (Goodley & Tregaskis, 2006)

Disability: It defined as the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (Goodley & Tregaskis, 2006)

Disabled individual: The term disabled individual usually refers to those people who differ from the average in that the society easily perceives them as requiring special education, social, or vocational education (Gargiulo, 1985).

Multi-disability: the individual who has more than one disability in different developmental areas in that they could have physical problems, at the same time intellectual challenges, profoundly mentally retardation or hearing impairments. For example, physical or neurological difficulties can be seen in these children and they may have severe impairments of language, other communication disorders, or impairment of body movements (Gallagher & Anastasiow, 1997; Batshaw & Perret, 1992 as cited in Kirk, 1972).

Family Systems Theory: The concept that emerges from the general systems theory and is explained as the theory which tries to understand and bring an in-depth perspective about the interaction, relation and adaptation among the family members (Lambie, 2000 as cited in Culatta & Tompkin, 1999; Chibucos, Leite, & Weis, 2005).

CHAPTER II

REVIEW OF LITERATURE

This chapter presents a literature review of multi-disability and how it affects the mother and the family context. The purpose of this review is to understand the issue from many perspectives. Hence, this chapter includes a general introduction on disability, and a synthesis of the literature on multi disabled children, family systems theory, disability in family systems, effect of disability on the mother, parents, and siblings. This literature review will also offer a brief explanation of the emergence of multi-disability in the literature and how parents cope with the issue.

2.1. General Introduction on Disability

It is believed that all individuals are unique and there are some similarities and differences among them. All children show differences from one another. In addition, all students present different skill levels in academic subjects and different interest levels in educational activities. Also, children show differences from one another in terms of their physical characteristic and learning abilities. However, it is the degree of these differences that determines whether a child is exceptional and therefore suitable for special educational services.

The definition of “normal” or “acceptable” in our (Turkish) culture is difficult to understand. People within a group may be characterized as normal when they become similar to the group’s rules or social values. When individuals meet the social and educational expectations of the group, they are considered as normal. The term disabled individual usually refers to those people who differ from the average in that they are easily identified by the society as requiring special education, social, or vocational education (Gargiulo, 1985). Disabled children may have some developmental delay in thinking, seeing, hearing, speaking, socializing or moving. Because of these reason,s these children need special education and services which provide physically and socially good conditions for them (Hallahan & Kaufman, 1988).

Information related with the disabled children goes beyond the ancient times. In ancient times it was reported that disabled children were neglected, abused or killed. There are basically three reasons for this:

According to the principle of "usefulness" disabled children were considered to be useless for both the family and the society. It was believed that disabled children meant "responsibility". They permanently needed a person to take care of themselves; therefore, they prevented their caregivers from participating in the society. In other words, it was believed that they were a load for the family and the society.

The second reason for the lack of sympathy for disabled children was social norm values. In ancient times at B.C. 355 the famous saying of Ariston "do not allow anything imperfect to develop" affected Greek and Rome societies. They encouraged beauty, power and intelligence. However, the disabled individuals, who were out of these perfect terms, were eliminated. (Morgan, 1987 as cited in Ataman, 2007).

The third reason for the neglect and abuse of disabled children was belief in supernatural powers. Families of disabled children believe that a particular child was given to them as a punishment from God. Families believed that they should kill their children and send them back to God. It was also believed that these children had sinful souls. Thus, in order to save them from this, people killed these children (Morgan, 1987 1987as   Ataman, 2005).

In the middle ages, disabled individuals were used as “fools" or "jesters" to entertain the lords and their ladies. Moreover, in the period of Protestant Reformation most people believed that disabled people were controlled with the devil and therefore people tortured them (Rothstein, 1967).

One of the important movement occurring in these ages was the teachings of Luther and Calvin. They affected the Church in that it preached that disabled children should be protected. From that time, religions began to behave more honorably and started to increase bit by bit the protection of disabled children (Rothstein, 1967).

From the thirteenth century onwards, the churches of Europe began to shelter these less fortunate members of society. However, there were not any attempts for their treatment or education (Rothstein, 1967).

The philosophy which influenced the thinking of most professional persons of that day brought confusing concepts which was “nature vs. nurture” controversy including the disabled people. This controversy debated whether growth and development was affected by heredity or environment. Before 1800, the “naturalists” were of higher authority. They supposed that heredity was the primary cause of disability and it was not curable. This idea prevented the possible treatment and education fro disabled individuals. They believed that the handicaps of disabled people were permanent; hence, there was no way to overcome it (Rothstein, 1967).

The history of the practice of professional treatment of the disabled dates back 150 years. It is just over a century old in present century. One of the first professional persons who started professional treatment for disabled individuals was the French physician, Jean Itard. He did not agree with the teachings of the "naturalists" and applied the teachings of John Locke of England and Jean Rousseau of France. According to their point of view learning emerges through the senses and with given adequate stimulation all persons could develop the ability to learn. They were completely against the "hereditarians" and "naturalists." They were “environmentalists" and "sensationalists." It was reported that from approximately 1800 to 1805, Dr. Itard educated a boy who was diagnosed by the great physician Pinel as severely retarded. Initially, he taught him intensively, emphasizing sense and motor training. Although remarkable development occurred in the behavior of this boy as the result of the education, Itard was unable to teach him to talk or to live independently in the Parisian society. This was the first scientific attempt at training a retarded child though Itard viewed his experiment as a failure. This attempt was considered as a new movement where professional personnel assumed responsibility from the Church for the retarded. Another contribution of this movement was that it marked a radical change of emphasis from incurability and custodial care to treatment and education (Rothstein, 1967).

Recently, taking inspiration from Itard’s creative and systematic approach, professionals used appropriate techniques for training disabled individuals (Rothstein, 1967).

2.2. Multi-Disabled Children

Children with severe and multiple disabilities may have an extensive range of physical and intellectual problems. Some of these children's disabilities are so severe that they need intensive help or support for their entire lives. Also, many of them are profoundly mentally retarded. On the other hand, few of these children with severe and multiple disabilities may be cognitively gifted and talented. Some of them are able to walk, but others may need wheelchairs or other prostheses such as crutches or braces to walk or provide their needs. Physical or neurological difficulties can be seen in these children and they may have severe impairments of language, other communication disorders, or impairment of body movements (Gallagher, & Anastasiow, 1997; Batshaw & Perret, 1992; as cited in Kirk, 1972).

Multi-disabled children may have auditory impairment. Kirk (1972) defines those with an auditory handicap as the individuals who have difficulty hearing in one or both ears or may not hear at all. In the literature, there are various terms referring to the auditory handicapped like "hard-of-hearing," "deaf," "deaf-mute", "deafened", "partially deaf," and "partially hearing,". According to Kirk (1972) most of these terms are used to differ auditorialy handicapped children from others. He gives an example as:

> The deafened usually refers to someone who once had hearing and developed language and speech, and later became deaf. Such an individual's reactions in the field of learning and communication are quite different from those of a person who was born deaf and never learned to speak or communicate verbally (p. 239).

Streng (1958 as cited in Kirk, 1972) defines the auditory handicapped as follows:

> The child who is born with little or no hearing, or who has suffered the loss early in infancy before speech and language patterns are acquired is said to

> be deaf. One who is born with normal hearing and reaches the age where he can produce and comprehend speech but subsequently loses his hearing is described as deafened. The hart of hearing are those with reduced hearing acuity either since birth or acquired at any time during life. (p. 239)

In terms of social adjustment and social interaction many hearing-impaired children have difficulties. This is because hearing-impaired children can not interact socially as hearing children do. Furthermore, hearing-impairment creates various struggles not only in social adjustment, but also in the educational progress, which is an important part of social context, especially in the areas of speech and language (Kirk, 1972).

Multi-disability may also contain cerebral palsy within itself. While "cerebral" means "brain" and "palsy" means "a motor disability," cerebral palsy refers to a motor disability caused by a brain dysfunction. Cerebral palsy not only causes brain damage which results in the motor disability, but it can also cause language, speech, writing, and other disorders. In addition to this, cerebral disorders can cause psychological disorders without affecting motor ability (Kirk, 1972).

United Cerebral Palsy research and Educational Foundation formed an inclusive definition as (1958 as cited in Kirk, 1972):

> Cerebral palsy embraces the clinical picture created by the brain, in which one of the components is motor disturbance. Thus, cerebral palsy may be described as a group of conditions, usually originating in childhood, characterized by paralysis, weakness, incoordination or any other aberration of motor function caused by pathology of the motor center of the brain. In addition to such motor dysfunctions, cerebral palsy may include learning difficulties, psychological problems, sensory defects, convulsive and behavioral disorders of organic origin. (p. 353)

As well as the neuromotor component in the definition of cerebral palsy, many other mental or psychological disabilities of the perception, learning, emotions, and speech can be in the definition of cerebral palsy (Kirk, 1972). It was explained as:

> The cerebral dysfunction resulting in cerebral palsy also may cause a variety of other handicaps, singly or in combinations. As in neuromuscular disabilities, where cerebral palsy can affect one arm, or one leg and one arm or both legs and both arms, a cerebral dysfunction may cause none, one, or a number of significant deviations: intellectual defects, left-handedness, deficiencies in vision, hearing, speech, or visual-motor perceptions. (p. 354)

It also reported that often poor speech and uncontrolled writing or spastic movements of cerebral-palsied children may give the society the impression that these children are mentally retarded. In fact, there is actually little direct relation between intelligence and degree of impairment in cerebral palsy (Kirk, 1972).

The general characteristics of children with severe and multiple disabilities show wide behavioral differences and characteristics and there may be some differences and similarities among individuals with severe and multiple disabilities (Guess & Siegel-Causey, 1988 as cited in Kirketal., 1997). Although there are such differences and similarities, there are some general characteristics. These general characteristics can be discussed under the titles of intellectual functioning, adaptive behavior, physical and sensory development, health care needs, and communication needs. The following paragraphs provide a comprehensive, but brief review of characteristics of individuals with severe and multiple disabilities.

To begin with, in terms of intellectual functioning although many individuals with severe and multiple disabilities have severe impairments in intellectual functioning as determined by standardized intelligence test scores, some of them may represent normal or high intelligence (Turnbuil, Turnbull, Shank, & Leal, 1995 as cited in Kirketal., 1997).

As for academic skills, most individuals with severe and multiple disabilities cannot perform traditional academic tasks, although some of these students can benefit from functional, educational, and academic skill programs (Giangreco et al., 1997 as cited in Culatta & Tompkins, 1999). If supportive and sufficient cognitive abilities were given to these children, they can succeed in general education classes. (Giangreco et al., 1997; Turnbull et al., 1995 as cited in Culatta & Tompkins, 1999).

Self-care skill of children with severe and multiple disabilities, could also be improved with appropriate support. They can learn to care for their own needs such as dressing, personal hygiene, toileting, and feeding, and may successfully master some household chores (Kirk, 1972).

Another important concept is social skills. Most of these children do not have typical social skills or the opportunities for social interactions that might allow them to develop social skills. Additionally, some are withdrawn by the society, or conversely, too assertive. On the other hand, reports point out that these individuals can engage in reciprocal interpersonal relationships with teachers and family. Hence, the society should provide enriching opportunities for participation in the community, with appropriate employment and living situations for these individuals (Hardman et al., 1996; Bradley & Knoll, 1995 as cited in Culatta & Tompkins, 1999).

Another general characteristic within these children is delayed motor development. Individuals with severe and multiple disabilities usually show a significant delay in motor development, including sensorimotor impairments and abnormal orthopedic muscle tone. Nevertheless, most of them with proper assistance can learn to walk (Turnbull et al., 1995; Nisbet, 1992 as cited in Culatta & Tompkins, 1999).

Sensory impairment including hearing and vision impairments are common among individuals with severe and multiple disabilities, with the most impaired individuals being deaf-blind. Downing and Eichinger (1990 as cited in Culatta & Tompkins, 1999) reported that there may be diverse combinations of sensory impairments that occur with normal or gifted individuals.

2.3. Family Systems Theory

In this present study the family system theory is the basis of the theoretical framework. This theory examines the family dynamics and relationship among family members which contribute to a core understanding for the case of my study. In this section, the definition of family, general theory, family systems theory and its components are explained in detail (Culatta & Tompkin, 1999).

Family is generally known as a significant factor in the physical, spiritual, and emotional well-being of its individual members. It is a cycle that goes through a series of developing and repetitive actions about the emotional well-being of its individual members (Freedheim, 1992). Related with this definition a family is seen as a system in that family members interact with one another, show consistent behaviors, and share some degree of interdependence (Lambie, 2000 as cited in Culatta & Tompkin, 1999).

A system is viewed as a set of interconnected elements surrounded by a boundary and showing common characteristics or quality in general systems theory.

Family systems theory's heritage derived from the work of Ludwig Von Bertalanffy's work on general systems theory. (Chibucos, Leite & Weis, 2005). A systems perspective states that there is relation among the component of the system and they affect other components and are affected from others. Unlike the mechanistic models of the time, von Bertalanffy's general systems theory argued that organisms are complex, organized, and interactive (Klever, 2005). A general systems perspective delays the quality of this interaction among the components of a system and how these components come together to from a whole. A systems perspective concentrated on examining the whole rather than the each part of the system (Culatta & Tompkins, 1999).

In the 1920s, the main components of the family systems theory emerged. By the end of the twentieth century, the family systems theory had become one of the major theoretical foundations and it started to direct empirical investigations into family studies. After that, clinical interventions and programmatic work with families began to be developed (Freedheim, 1992).

The implementation of the systems perspective has special relatedness to the study of the family. Since families participate in the same historical background, there is an emotional connection between them and they share the same goal in order to satisfy needs of individual members and the family as a group (Pinku, 2006). A basic idea in family systems theory is that the family includes interconnected members, and each member affects the others in predictable and repeating ways.

Family systems theory allows one to grasp the meaning of the organizational intricacy of families and the communicating models that direct family communication; hence, the theory concentrates upon family behavior rather than individual behavior. The theory takes into account communication and interaction patterns, separateness and connectedness, loyalty and independence, and adaptation to stress in the context of a whole as against the individual in isolation. Also, family systems theory can elucidate the reason behind the family members' behaviors. Tier behaviors basically composed of two factors which are processes within families, and between families and their environments (Chibucos, Leite & Weis, 2005).

From a family systems theory perspective, a family can be seen as a machine because it is comprised of a set of interconnected elements that together make a coherent whole (Morgan, 1988). It is also viewed as a machine because an engine receives meaningful inputs and its parts are all appropriately connected. A family is also like an engine which reflects both inputs received by the family and patterns of interaction among members of the family (Chibucos, Leite & Weis, 2005).

Family systems theory includes a number of key concepts including independent components, inputs and outputs, boundaries, hierarchy of systems, rules, goals, feedback mechanisms, nonsummativity, change, and equifinality (Chibucos, Leite, & Weis, 2005).

The concept 'interdependent components' of the family system are the members of the family and the roles they perform. Among the family members there is a degree of dependence. Individual family members that include the family system are reciprocally affected by and are mutually contingent on one another. What happens to one family member, or what one family member does, influence the other family members (Winick, 1996). These are factors which make the family member hold on to one another. The interdependence that exists among family members is not only the glue that holds family system together, but it also explains the nature of relationships in families. All members of the family system are impacted by a change in another member (Chibucos, Leite & Weis, 2005). The alteration affects the family as a whole.

The other concept is 'inputs and outputs'. The information received by the family that may impact family functioning is defined as inputs. These inputs in the form of messages or information may be received by the family from outside. Outputs reflect the things received from inputs as speaking and behaving (Chibucos, Leite & Weis, 2005).

'Boundaries' are another concept within the family system. Around each family system a boundary exists (Chibucos, Leite & Weis, 2005). In the family system, boundaries relate to limits, togetherness, and separateness. Families decide on boundaries in terms of what is contained in the family system and what is external to the system. Boundaries exist at every level of the system and between subsystems (Perosa, 1980 as cited in Winick, 1996). They influence the behaviors of people in and out of the system. In addition to this, they regulate the flow of information into and out of the family. Boundaries also often distinguish one family from another. Boundaries are described by degrees of strictness that affect how much information is permitted into or out of a family system. The presence of very rigid boundaries suggests that a family is less influenced by events and information from its environment and that family members are isolated from the environment (Chibucos, Leite & Weis, 2005). For instance, some families are open to new people, information, and ideas. Some family members are inclined to be autonomous, hence, make decisions on their own. Over a sense of belonging, family members give importance to separateness and autonomy. Each person's individuality is supported and admired. The families who demonstrate such kind of bounders among each other are described as disengaged. However, in other families boundaries tend to be more restricted and limiting in that the families show importance of togetherness, belonging, emotional connectedness, and sometimes agreement (Winick, 1996). The families who have rigid boundaries prefer to control rather than monitor their children's friends and activities.

'A hierarchy of systems' is another concept that exists within and beyond family systems. It describes how families arrange themselves into several smaller units or subsystems that together include the larger family system (Chibucos, Leite & Weis, 2005). Relationships among family members are reflected by subsystems. Like the boundary around the family system, each subsystem is encircled by a boundary with degrees of permeability. Moreover, various subsystems may have different levels of power within the family system. Power in family systems is typically held by the members of the subsystem that are higher on the hierarchy of subsystems within the family (Chibucos, Leite & Weis, 2005). For example, in some families, the hierarchy is a parental one. The parents share family responsibilities. Although there is a clear balance and power of control in families, one may respect the other dependent upon a particular situation or individual might. Family hierarchies rely on gender and age and are affected by culture, religion or economic status. Sometimes, there could be a clear and strong message which determines the behavior of the family members received from the dominant member in the family but other times it may be hard to recognize. In other families, the elder grandmother might be the decision maker, and family members give importance to her leadership and guidance. For some families the role of extended family in hierarchy may be very significant (Silverstein & Ruiz, 2006).

Additionally, subsystems are often organized by gender or generation. Practitioners generally have focused on three primary subsystems. The first one is marital (or couple), second one is parental, and third one is sibling. To be able to accomplish the tasks and goals of the family, members of the family may organize themselves into subsystems. Families may have some difficulties when the members or tasks related with each subsystem become blurred with those of other subsystems. For instance, when a child becomes involved in the issues of the marital subsystem, difficulties often emerge that require intervention. Especially if the child is disabled this may cause the parent to experience more challenges (Knoblock, 1987).

Another important concept within the family unit is ‘rules’. Rules are defined as “sets of standards, laws, or traditions that tell us how to live in relation to each other” (Chibucos, Leite & Weis, 2005, p. 280). In the family system rules have the role of reflecting repeated patterns. They reflect patterns of relationship that serve to prescribe family members' behavior, roles, patterns of authority, expression of emotion, and communication. (Chibucos, Leite & Weis, 2005). Furthermore, rules are implicitly understood by family members and they may be spoken or unspoken. Rules are often inserted into a cultural context. Hence, they can donate to the feeling of cultural discontinuity that children live through in social environment. (Fingerman & Bermann, 2000).

Apart from these, ‘goals’ is the other concept that takes place in family systems. While family members grow and change, goals also change over time. This concept suggests that family interactions and behaviors are goal-oriented. This means that these goals derive from the rules and boundaries of the family system. It is important to consider that goals exist at the family system level and may not always coincide with goals of individual family members (Chibucos, Leite, & Weis, 2005).

The concept of ‘feedback mechanisms’ is used to describe the patterns or channels of interaction and exchange of information or ideas within the family. In order to monitor their status, families reflect many feedback loops or patterns. They can be either negative or positive. Negative feedback loops are those patterns of interaction that provide solidity or steadiness while minimizing change. Positive feedback loops, in contrast, are forms of interaction that promote or alter movement toward either growth or disintegration. The concepts of negative and positive feedbacks do not refer to the communication as good or bad within the family system (Winick, 1996). From a systems perspective, families struggle to keep equilibrium in their functioning. Also they are constantly monitoring the degree to which their functioning is consistent with system goals. If it is seen that there is an inconsistency among the family members’s behaviors and attitudes towards each other then they use the concept of “change” to maintain balance (Chibucos, Leite, & Weis, 2005).

‘Nonsummativity’ is the concept that while family systems are composed of a set of elements or parts, the system cannot be simplistically viewed as the sum of its parts. Definition of the family system includes the concepts that are patterns of interaction, emotional and instrumental connection, and functioning. In other words, all of these factors contribute to the family system. Therefore, family systems theory addresses both the structure of families and patterns of interaction that exist within families and between families and their environment as a whole. (Chibucos, Leite, & Weis, 2005).

The concept of ‘change’ is defined as the adaptation to new patterns of interaction in response to information that is received either from outside the family or within the family. Often this need for change is reflected in changing developmental issues or necessity. Therefore, a family system reflects a pattern of morphogenesis which means a tendency to change its basic structure or functioning over time. In order to understand the family system it is important to consider the processes and patterns of change in the family (Chibucos, Leite & Weis, 2005).

The last important concept is ‘equifinality’. It is defined as “the ability of the family system to accomplish the same goals through different routes” Chibucos, Leite & Weis, 2005, p. 280). Equifinality suggests that the same beginning can result in many different outcomes, and that an outcome may be reached through many paths. Thus, families may use one or more of these methods to achieve the same goal (Chibucos, Leite & Weis, 2005).

2.4. Disability in Family System Theory

Family Systems Theory is the framework of this study because it recommends that the family have value and meaning when all the parts of it are understood completely and as whole. Since a family system is more than the sum of its parts, this theory tries to examine the disabled children and interaction of them with their family members; mother, father, and sibling (Stoneman, & Gavidia-Payne, 2006; Ryan, Campbell, Rigby, Germon, Chan & Hubley, 2006; Weiss ,1997; Chibucos, Leite & Weis, 2005).

Disability of a child has an important influence on different aspects of the family system. The influence of the disability of the child on the interaction within the family members, including parents, siblings, and the family as a whole is examined in this part. Additionally, this section includes the studies that investigate this interaction among family members, parental emotional state in terms of disability in family unit and the potential stress that family members have because of the presence of a disabled child. Not only the affect of the disabled child, but also the affect of the family on the disabled child is discussed in the light of the studies (Chibucos, Leite & Weis, 2005).

2.4.1. The Interrelation between the Disability and Family System

In order to examine the disabled child and the disability in a family setting the perspective of family system theory will be useful, since family members are a part of a living system, which operates according to established rules and principles. According to Von Bertalanffy's general system theory (Chibucos, Leite & Weis, 2005) there is continuous input to the system, which is acted upon and modifies its members. There is also continuous output to the environment.

A family is responsible for the care of all its members including the disabled member. The most basic function of the family is to provide its members with economic support and physical care, but equally important is the family's emotional functioning, providing a safe and secure environment, and creating support and guidance (Hallahan & Kauffman, 2003). However, it is likely that families of children with disabilities will experience feelings, burdens and stresses that families of nondisabled children will not experience. The child with a disability will have a major influence on the structure, function and development of a family. The presence of a child with a disability affects each family member, as well as a unit. As many studies have showed, the person in the family that is most likely to be affected by a child’s disability is the mother (Hassall, Rose & McDonald, 2005).

Roberts and Lawton’s (2000) findings showed that although all children require parenting, the care parents provide for disabled children generally exceeds that provided for a non-disabled child. The findings approve that the severely disabled need important care in many areas of daily life. Parents are informed about the extra care they need to give to their disabled children from professionals (Roberts & Lawton, 2000).

It is expected from all parents to care for their children. This care is more extensive during infancy in every aspect of the child’s development such as, bodily functions and physical, mental and emotional development. The care required changes and diminishes as the child grows. Like all children, severely disabled children require the same care from their parents. Moreover, they need extra care because of impairments or chronic ill health (Roberts & Lawton, 2000).

A study conducted by Traustadottir (1991) examined how gender relations shape roles, responsibilities, and division of labor within families of children with disabilities. In addition to this he investigated how caring for a child with a disability influences the life of the primary caregiver. He reported that caring is seen as a women's responsibility, and the division of labor assigns far more responsibility for caring to women than to men. Besides this the mother was seen as the "natural" caregiver, both in terms of doing the work and giving the love. In general the terms work and love combined with the mother rather than other family members. Hence, this social belief creates a pressure on the mother and she is seen as the person who devotes her whole life to her child, her family as well as to her disabled child or children. Moreover, mothers of disabled children extend their care beyond their own child to broader community or societal concerns. This is what the society expects from the mothers (Traustadottir, 1991).

Apart from this, unlike the traditional mother roles, mothers of children with disabilities have a more complex caring role. Most of the mothers with disabled children are active in that these mothers spend much of their time advocating both on behalf of their own child and on behalf of people with disabilities in general and are active in creating social change. They join meetings, lobby legislators, pressure the school board, argue with government officials, organize parents' groups, and so on. All these activities make the mothers of disabled children different from the traditional female activities of other mothers. Hence, in this case mothers of children with disabilities perform complex and extended roles (Traustadottir, 1991).

It is also mentioned in the research that it is mother’s role to take the responsibility of the disabled child within the family. On the other hand the primary role of the father is to be a supporter. Traustadottir (1991) stated that:

> The gender roles and responsibilities within families of children with disabilities reveal a division of labor that follows a very traditional pattern where the father's primary responsibilities are related to the world outside the family, and the mother's responsibilities are within the family. (p.221)

Ozgun and Honig (2005) studied parental involvement and spousal satisfaction with division of early child care in Turkish families with normal children and children with special needs. As a general point of view about rearing typical or atypical children, mothers reported a higher level of involvement than fathers in every domain of child care. In general in terms of participating in child care process, both mothers and fathers reported slight dissatisfied. Ozgun and Honig (2005) stated that across groups, all mothers were significantly more dissatisfied with the fathers’ level of participation in child care.

As previously mentioned, equifinality is one of the components of a living system. Different initial conditions may lead to the same results and different results may come from same causes (Chibucos, Leite, & Weis, 2005). Hence, in a family the initial condition or event will be more important by the family’s ongoing interactinal patterns and responses to the stress. The disability has an effect on its members’ reactions as well as their stress level (Argyrakouli & Zafiropoulou, 2003). According to Argyrakouli and Zafiropoulou (2003) raising a child with an intellectual disability certainly causes additional stresses, which can lead to lower levels of maternal, general and social self-esteem.

A study on families with deaf and hard of hearing children aimed to investigate the correlation between parental resources, socio-demographic variables, parental stress experience, and child socio-emotional problems. The results of the study indicated that high parental stress is associated with frequent socio-emotional problems in children. The results also revealed that parents with additionally handicapped children are especially stressed and the child's communicative competence makes for a more sound prediction than its linguistic medium (spoken language or sign) (Hintermair, 2006).

2.4.2. Family Structure and Disability

Salvador Minuchin (Chibucos, Leite, & Weis, 2005) developed the structural approach within the family system theory. According to him, the family is determined by structure, function, boundaries between subsystems, and degrees of functional attachment among individuals. He defines the family as nuclear family or household. Family structure describes the continuous modes of interactions of the family members or subsystems with each other. He states that "family structures are formed by cultural expectations, those of the family origin models, extra family social relationships and life stressors" (Chibucos, Leite, & Weis, 2005, p. 254).

Family members who join together for various functions come to gather and form the subsystems. A member in the family may have roles in more than one subsystem. There are some subsystems in a family who have a disabled member. One of them is the marital subsystem, which involves the interaction between the marital partners. Second one is the parental subsystem, which contains the partners' interaction with the both the disabled child and other siblings. Mac Donald (2006) states that, in families of disabled children mothers tended to use more ‘problem solving’ strategies than fathers. Fathers tended to use more ‘managing meaning’ coping strategies than mothers, although some strategies were shared across genders.

Hedov, Annere, and Wikblad (2002) studied challenges to the adjustment ability in parenthood in parents of a child with Down’s syndrome. The study aimed to find out parental self-perceived stress, coherence, frequency of gainful employment and amount of time spent on child care in Swedish parents of a child with Down’s syndrome. The findings showed that parents with high coherence scores experienced significantly less self-perceived stress.

The variations in the relationships among child characteristics, parenting stress, and parental involvement was examined. Results indicated that there was a different connection between child temperament and parental stress for mothers and fathers. It was mentioned that there were more significant associations were between perceptions of child temperament and involvement for fathers than for mothers. On the basis of child and parent gender there were different associations between child temperament and parental stress and involvement (Mcbride, Schoppe & Rane, 2002).

Another subsystem is the sibling subsystem, which involves interactions among the siblings, including the disabled child. Rodger and Tooth (2004) said that in comparison with other members in families where there is a child with a disability, siblings have received relatively less attention, both in the research literature and in terms of access to support services. Increasingly, it is recognized that families with a child with a disability offer siblings unusual opportunities for growth and maturation and development of qualities, such as sensitivity, nonjudgmental attitudes, and awareness of individual differences (Featherstone, 1980; Levitt, 1993; Meyer and Vadasy, 1994 as cited in Rodger and Tooth, 2004). The last one is the extra family subsystem, which is composed of the extended family, friends, and members of the community (Morga, 1988).

In order to be mutually supportive and permit growth and development in the family, the functions of each subsystem need to be well defined. However boundaries sometimes may disrupt the function among the subsystem. For instance, in the family of disabled child, care giving responsiblilities may be loaded on the mother rather than other family members (Morga, 1988).

In any of the systems the components of the system rely on each other and the system functions as a whole (Minuchin, 1985 as cited in Morgan, 1988). Also, the system has certain internal stability features that eternalize the stability of its patterns. For instance, in well-functioning families where the system is more open, this self-regulatory process tends to be adaptive. However, dysfunctional families where the system becomes less open and more resistant to change, can incorporate maladaptive patterns as necessary components of the system (Morgan, 1988).

Boundaries within the family may have negative sides in that there can be a lack of warmth and nurturance. If the parents of a child with a disability may be so involved in the grieving process over the loss of a perfect child, they are disengaged not only from their special needs child, but from their other children as well. Another point of view is the boundaries in the family in which there is disabled member, the mothers’ primary responsibilities are still considered to be within the family, and the bulk of housework, child rearing, and caretaking remains women's work (Traustadottir, 1991).

The family system is affected most directly by the presence of a disabled child. This event has an impact on the family interactions such as the relationship between the parents as well as the relationships between the parents and other children in the family. The effect and relation is mutual in that the disabled child not only has effects on the family but the family has effects on the behavior and adjustment of the child (Morgan, 1988). This effect unlike the general view may strengthen the relationship among the family members and may affect the quality of life positively. Brown, Anand, Fung, Isaacs and Baum (2003) conducted a study on gathering preliminary data on the quality of life of families that have children with disabilities. The contributors to family quality of life were spiritual and cultural beliefs, family relationships, and careers. The findings of the study demonstrated that although many challenges were identified such as increased responsibilities for the care for sons and daughters with disabilities, many families perceive that they were able to maintain a satisfactory level of quality of life and families found ways to remain positive. Brown et al. (2003) states "Having a child with a disability in family results in family dynamics and relationships among family members that are different from other families” (p. 208). Disability of the child results in some considerable changes over time. This change may occur because of the uncertain health status of the child, or the increase of the responsibilities of the family members. The Family may reflect these changes either with conflicts among themselves or the family may become stronger and closer with each other (Brown et al., 2003).

Singh (2003) conducted a longitudinal study exploring the impact of a child's spina bifida, a nervous system deformity, on the family from different dimensions or aspects of family system. The result of the study showed that despite the unique challenges of raising a child with a disability, families are carrying out their responsibilities with successful outcomes. There is research on the parents of children with mental retardation that shows that as a result of parenting a child with a disability, parents have experienced increased personal growth, improved relations with other fellow beings, and changes in spiritual and philosophical values (Scroogie and Sobsey, 2000 as cited in Singh, 2003).

Unlike the research previously mentioned a recent study aimed to examine the relationship between parenting styles and parental stress in children with developmental disabilities across two age groups. Woolfson and Grant (2005) stated that parenting children with developmental disabilities is indeed more stressful and problematic than parenting typically developing children. The results demonstrated that parents of children with developmental disabilities have a higher score on all stress measures than those typically developing. The results Woolfson and Grant (2005) suggested that parental coping support interventions are required for parents of children with developmental disabilities, as well as interventions to directly help with parenting skills in child behavior management. Additionally, they point out that some parents may need emotional and social support in the stressful task of parenting children with developmental disabilities, especially when they are trying to help set behavioral limits.

In Turnbulls' (1997 as cited in Hallahan & Kauffman, 2003) family system model, family members connect to one another in functional and dysfunctional ways. He states that cohesion and adaptability are seen as important determinants of how family members interact with each other. In general, families are healthier if they have moderate degrees of cohesion and adaptability. He describes the cohesion as a degree to which an individual family member is free to act independently of other family members. If there is an appropriate amount of family cohesion in the family, the individual can be his or her own person while at the same time drawing on other family members for support, as needed. On the other hand, families in which there is low cohesion may not offer the child with a disability the necessary support. In addition, the overly cohesive family may be overprotective towards the disabled child. Both cases make the situation difficult in that none of them may provide the appropriate needs of the children with disabilities. To help the disabled children in the appropriate time and amount without infringing on their freedom, the parent may give them family based responsibilities. A study reported that in the early years supportive help of the parent has a useful affect on disabled child. In a study, mothers of toddlers with Down syndrome who during play engaged in more helpful behaviors such as steadying objects and otherwise making it more likely that the children would experience success had children who were more likely to play and vocalize (Roach, Barratt, Miller & Leavitt, 1998; as cited in Hallahan & Kauffman, 2003).

The disability is examined with concept of adaptability that refers to the degree to which families are able to change their modes of interaction when they face unusual or stressful situations. In a family living in an unstable environment, the needs of the family member who are disabled may be overlooked or neglected. In extremely rigid families adjustment to disability itself and the disabled member may be difficult. Adjustment to this undesired situation is very important. For instance, the arrival of a disabled member to a family introduces new duties onto family members. For example, a mother may need to be involved in transporting the child with a disability from one therapy session to another. Moreover, while the mother is dealing with that responsibility father should adapt to this new condition and involve in house-hold jobs and taking care of the other children (Hallahan & Kauffman, 2003).

Family functions are the numerous routines in which families engage to meet their many and diverse needs. Economic, daily care, social, medical and educational needs are just a few examples of the functions to which families need to attend. With the presence of the disabled child in the family system all these functional needs may increase and change (Hallahan & Kauffman, 2003). In 2005, Burstein, Bryan, Chao, Berger, and Hirsch studied comparing the communication patterns of pediatricians with parents of children with special health care needs and parents of healthy children to explore whether there were significant differences in communication patterns and satisfaction. Results showed that although pediatricians did not differ in their frequencies of communications, parents of children with special health care needs contributed more medical-related information and had higher rates of social exchanges and questions than parents of healthy children. Results also revealed that children with special health care needs also participated more than healthy children. Additionally the results emphasize the role of parents of children with special health care needs in communicating medical information, as well as the importance of pediatrician–family relationships to families of children with special health care needs.

Several family theorists have noted that the impact of a child with a disability on the family changes over time (Berry & Hardman, 1998; O'Shea, Q'Shea, Algozzine, & Hammitte, 2001; as cited in Hallahan & Kauffman, 2003). For this reason, some have pointed to the value of looking at families with children with a disability from a life-cycle perspective. The family life cycle is identified as the progresses within the family and predictable stages in its development. Families of children with disabilities will find this progression more challenging (Wall, 2003). A family with a retarded or physically disabled child may have been able to adapt when the child was young, but as he/she grows older and the disparity between the child and peers is more apparent, stress may onerload the family system and dysfunctional patterns may appear (Bowe, 2004).

Most family theorists consider four stages in the lives of families as early childhood, childhood, adolescence, and adulthood. For families especially families with children who are disabled transitions between stages in the life cycle are particularly stressful. Children with disabilities who are entering adulthood need guardianship. In such cases, families face with some difficult issues (Berry & Hardman, 1998 as cited in Hallahan & Kauffman, 2003).

The literature clearly reflects that the birth of a disabled child is an event that has great impact on nearly every aspect of family life. Furthermore, the nature of the child's disability may further confuse the family's situation and future expectations. The presence of more than one handicapping condition affect whole family in terms of interaction among members, subsystems, function of the family and family life cycle. Families face with some decision-making situations such as how to care for their disabled child, and where to place their disabled children to have a special education institution or a rehabilitation center. To make such decisions may increase stressors and they can have significant impact on family structure and dynamics.

2.5. Effects of Disabled Child on Parents

Disability and a disable member particularly affect the parents, parental interaction and communication between each other as a couple and other family members. This unexpected condition leads parents to go through a series of stages. Researchers stated that some of these stages are similar to the person's reactions to the death of a loved one (Culatta & Tompkins, 1999). Based on interviews of parents of infants with serious physical disabilities, a representative set of stages includes (1) shock and disruption, (2) denial, sadness, anxiety and (3) fear, anger, and finally adaptation (Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975 as cited in Culatta & Tompkins, 1999).

Researchers also indicated that parents may not go through these reactions in a rigid fashion and some do experience some or all these emotions at one time or another. In fact, a commonly reported reaction is guilt.

In the feeling of guilt, parents see themselves as the reason of their children’s disability. Although there is definitely no basis for such thoughts in the large majority of cases, guilt is one of the most commonly reported feelings of parents of exceptional children (Culatta & Tompkins, 1999).

It was noted that occurrences of guilt is probably because of not knowing the cause of the disability with the baby. Therefore, firstly parents blame themselves. During this critical period, the cause of the child's disability creates an atmosphere in which the mother becomes particularly vulnerable (Culatta & Tompkins, 1999). Orsmond, Lin, and Seltzer (2007) examined the types of disabilities in siblings from a large sample of families of adolescents and adults with autism spectrum disorders and the impact of another child with a disability on maternal and family well-being. The results revealed that the mothers parenting another child with a disability had higher levels of depressive symptoms and anxiety and lower family adaptability and cohesion compared with mothers whose only child with a disability had autism spectrum disorders matched on child age and family size.

In a study of toddlers with pervasive developmental disorders Herring, Gray, Taffe, Tonge, Sweeney, and Einfeld (2006) pointed out that child behavior and emotional problems, parent mental health problems, parent stress and family functioning were significantly correlated, providing some evidence of stability over time. Moreover, it was noted that child emotional and behavioral problems contributed significantly more to mother stress, parent mental health problems, and perceived family dysfunction than child diagnosis of pervasive developmental disorders and developmental delay, or gender. Findings also demonstrated that compared with mothers, all fathers reported significantly less stress in relation to parenting their child.

Crabtree’s (2007) study of consideration of parental care in terms of gender differentials reported that although mothers carried the main burden of support, this situation has improved due to cultural interpretations of the role of motherhood as well as practical coping strategies. Furthermore, although countered by maternal strategies of resistance, discrimination towards disability as well as to gender is evident.

In a previous study by Benn and McColl (2004), the relationship between maternal and paternal coping, and the extent to which social support and family environment affect parental coping was investigated following an acquired brain injury of their child. The researchers found parents used coping strategies mostly. When mothers are compared to fathers, it can be seen that mothers had a more extensive repertoire than fathers, and the relationship between maternal and paternal coping seem to be completing.

Parental stress of the mothers and fathers of children with an intellectual disability was examined in another recent study (Saloviita, T., Italinna, M. & Leinonen, E. (2003). The researchers indicated that parental stress was caused by the negative definition of the situation. The negative definition was related with the behavioral problems of the child in the view of mothers. Differently, fathers connected the negative definition with the experienced social acceptance of the child.

Recent studies reported that fathers are not under as much stress as mothers, but fathers do have to assume more child-care responsibilities than before. In some cases it was found that both father and mothers experience relatively equal amounts of stress (Dyson, 1997 as cited in Culatta & Tompkins, 1999).

According to Trute, Hiebert-Murphy, Levine, (2007) both positive and negative appraisals appear to coexist and are predictive of mothers' and fathers' perceived overall family adjustment in the longer term.

In terms of parental reaction to stress it is stated that here is no universal parental reaction to the added stress of raising a child with a disability. It was considered that stress would be strongly related to the severity of the disability; however, there is little evidence to support this assumption. For example, parents of children with more severe disabilities may have greater child care burdens, but parents of children with milder disabilities may be more likely to experience additional stress related to that felt by parents of children without disabilities such as stress related with school achievement (Culatta & Tompkins, 1999).

Mostly there are two factors mentioned about how parents will cope with the stress affecting their psychological makeup and marital happiness and the quality and degree of informal support they receive from others. It is said those parents who were well adjusted and happily married before the disabled child have a better chance of coping with the situation than those who were already having psychological or marital problems. (Culatta & Tompkins, 1999).

There are several issues which help parents to cope with the stress of raising a child with a disability. These are initially social support that parents receive from each other, extended family members, friends, and others. (D'Asaro, 1998; Duis et al., 1997; Gavidia-Payne & Stoneman, 1997 as cited in Culatta & Tompkins, 1999). Additionally, received supports could be both physical such as offering child care, and psychological. In some situations, simply talking to someone may help the parents in their struggle to cope with the disabled child (Culatta & Tompkins, 1999).

In a study conducted by Plant and Sanders (2007), researchers found that the difficulty parents experienced in completing specific care-giving tasks, behavior problems during these care-giving tasks, and level of child disability, respectively, were significant predictors of level of parent stress. Furthermore, the results of the study showed that parents' cognitive appraisal of care-giving responsibilities had a mediating effect on the relationship between the child's level of disability and parent stress. Also, mothers' level of social support had a moderating effect on the relationship between key independent variables and level of parent stress.

Although most professionals supposed that parents of children with disabilities were destined for a life of stress and suffering, recently authorities have begun to find that many parents of children with disabilities end up adjusting quite well. The reason of this optimistic point of view is because of advances in educational and social programming for both parents and the disabled individual. In the early years of raising a child with a disability, some may experience high degrees of disruption and stress, but over time many come to learn to cope (Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001 as cited in Culatta & Tompkins, 1999). Gladly having interviewed some parents, noted that adding a child with a disability to the family actually has some unanticipated positive results (Scorgie & Sobsey, 2000; Skinner, Bailey, Correa, & Rodriguez, 1999). They report undergoing transformational, or life-changing, experiences, which include becoming more tolerant of differences in other people and more concerned about social issues.

All those positive views do not minimize the fact that the added stress a child with a disability often brings can have a saddening impact on the stability of the family. 5.9 million children are estimated to have with severe disabilities in the USA, and most of them are cared for at home by their parents and (Murphy, Christian, Caplin & Young, 2007). The researchers conducted a study on caregiver perspectives of the health implications of long-term informal caregiving for children with disabilities. From the collection of data, five themes emerged. These were stress of caregiver, negative impact on caregiver health, sharing the burden, worry about the future and caregiver coping strategies. It was found out that forty-one percent of the caregivers' health had worsened over the past year. In addition to a lack of time, a lack of control and decreased psychosocial energy were within these changes (Murphy, Christian, Caplin & Young, 2007).

In a study on 103 Canadian families, 103 mothers and 55 fathers, researchers examined the parental positive and negative appraisals of the family impact of childhood disability. The result of the study indicated that longer-term family adjustment was predicted by level of parental appraisal. In addition to this, for mothers, positive appraisal of childhood disability was found to predict early family adjustment and was related to enhanced self-esteem.

Twoy, Connolly and Novak, (2007) studied coping strategies used by parents of children with autism. The results of the study showed that parents of children with autism had resilience and a highly adaptive nature. Additionally, the results showed that the effective ways they coped as a family were in the areas of informal and formal social support networks. Also it was noted that participants used passive appraisal to cope. The study also supports the need for early recognition and diagnoses of autism and referral for early intervention for better outcomes for the children and families affected by autism.

As a result it could be stated that difficulty of care-giving tasks, difficult child behavior during care-giving tasks, and level of child disability are the primary factors which contribute to parent stress (Plant & Sanders 2007).

Glidden, Billings and Jobe, (2006) conducted a study on parental personality and whether children with developmental disabilities were adopted or born into the families and their influence on the coping strategies used by mothers and fathers. The results of the study indicated that parents with children with developmental disabilities face a variety of stressors associated with rearing their children. To cope with this stress, parents were expected to develop effective coping mechanisms in order to adapt successfully to these challenges.

Hastings, (2005) explored the use of reliable coping strategies including active avoidance coping, problem-focused coping, positive coping, and religious/denial coping of mothers and fathers of preschool and school-age children with autism. It was found that there were associations between coping strategies and parental stress and mental health.

Results of a recent study conducted by Hassall, Rose and McDonald (2005) revealed that there is significant relation among the parenting stress, parental locus of control, parenting satisfaction and child behavior difficulties. Furthermore, a strong correlation was found between family support and parenting stress in which parental locus of control had a role of mediation.

Hung, J Wu, and Yeh (2004) examined whether parental stress differs between parents of children with physical disabilities and parents of children with cancer. They worked with 92 parents with disabled children and 89 parents with children with cancer. The researchers reported that the parents of children with cancer experienced significantly higher levels of stress compared with the parents of disabled children.

Eccleston, Crombez, Scotford, Clinch and Connell (2004) pointed out that those adolescents with chronic pain showed high levels of pain intensity, anxiety, depression, disability and coping. Similarly, parents had high levels of anxiety, depression and parenting stress.

In Hastings and Johnson' (2001) study with 141 UK parents of children with autism reported that in terms of stress, coping, and support parents' stress levels were predicted mainly by psychological rather than demographic variables.

Furthermore, it is also risky to assume that the arrival of a disabled member to the family destroys the psychological well-being of the parents and stability of their marriage as well. It was stated that caregivers of children with disabilities describe negative physical, emotional and functional health consequences of long-term, informal caregiving. It was demonstrated that caregivers have both positive and negative affects of having disabled children on their health. Moreover, there is positive affect of intervention on the caregiver's health (Murphy, Christian, Caplin & Young, 2007).

2.5.1. Parental Anxiety and Stress

It is stated by Webster and Ward (1993) that there are many different patterns in parental anxiety of parental reaction towards the arrival of a disabled member to the family. It is a difficult situation which parents struggle through. Researchers and clinicians admit that there are some types of reactions parents will exhibit. In some families, having an exceptional child is a tragedy of the greatest magnitude. It is a crisis for some families but, one that can be resolved. Besides, for still others, it is not considered a problem in itself, but rather one element in a daily struggle for survival. It is also known that still most parents have had no previous experience with disabilities and are often unprepared to deal with them (Webster & Ward, 1993).

From the view of traditional perspective, parents of disabled child suppose that they will pass through several stages in their adjustment process. Generally, one moves through stage of initial shock and guilt toward a final goal of acceptance and adjustment (Gargiulo, 1985).

In the coming paragraphs these phases will be examined in detail. The first phase is primarily the phases in which there are concepts of shock, denial, grief and depression.

Most parents of handicapped children experience an internal response of overwhelming shock and disbelief. These occur with irrational behavior characterized such as excessive crying and feelings of numbness and helplessness. It was reported that many parents say that they were totally unprepared for the news of their child's handicap (Gargiulo, 1985).

Anther emotional reaction listed by the psychodynamic orientation is denial (Stanhope & Bell, 1981; Wetter, 1972 as cited in Knoblock, 1987). Some parents try to escape the reality of the child's disability and reduce the impact by rationalizing the deficiency, or by seeking professional confirmation that nothing is wrong with the child. (Webster & Ward, 1993).

Webster and Ward (1993) define denial in the case of disability in the family as a defensive posture. It occurs because of fear of the unknown the uncertainty of the child’s future potential. Additionally, parents’ doubts about being able to cope with the added responsibilities are brought on by the handicap.

Studies usually try to show denial in parents by comparing the parents' estimations of their children's abilities, with professional assessments of the same children. Another parental behavior related to denial is sometimes called “doctor shopping,” or “teacher shopping.” It means that parents are said to go shopping from doctor to doctor or teacher to teacher until they hear a prognosis optimistic enough for them to "buy" (Baum, 1962 as cited in Knoblock, 1987).

In this case Wolfensberger (1983) states that the professional literature seems to support parents to overcome the difficult fact which is sometimes unavoidable for the parents’ rejection of denial. Many parents will reject the use of certain labels such as mentally retarded, autism, learning disability, and hearing impairment. They find these labels repugnant and try to find a more acceptable reason for the disability (Heifetz, 1980 as cited in Knoblock, 1987).

Grief and depression is another stage that parents of disabled child experience. Parents are typically disappointed about having a handicapped son or daughter and they are realistically concerned about the future. Grief is a necessary and useful reaction and should not be avoided. It provides the parents with a transitional period through past dreams and fantasies about the “perfect child” and helps them to readapt to the reality that their child is disabled. There is no definite ending to the grief and depression. Some parents will continue to experience grief and disappointment throughout their lives (Gargiulo, 1985).

In Solnit and Stark’s study (1961) it was indicated that grief in parents is a two dimensional psychological process in reaction to the birth of a severely retarded child. Firstly, there is bereavement over the loss of the socially demanded and personally expected perfect infant. This is attached with shock and a move away from the defective child actually born.

On the other hand, depression is often an outcome of the grieving process. Depression is seen as anger turned inward, anger toward oneself. Parents are angry at themselves and angered at their weakness and powerlessness. Parents may also believe that they could prevent the event before it happens but they could not. These are the two produces of depression. Society considers depression to be inappropriate, a feeling that is not to be tolerated. However, it is part of a normal, natural process (Gargiulo, 1985).

The second phase of the parental reactions includes ambivalence, guilt, anger, shame and embarrassment. In the stage of ambivalence the parents see and are severely affected by their child's disability. The greater the disappointment, anxiety and depression the parents feel, the more they experience the negative and intensive feeling toward the disability and disabled child. Some parents even wish the child were dead. These negative feelings are usually accompanied by guilt (Gargiulo, 1985).

Guilt is perhaps the most difficult reaction for parents of handicapped children to overcome. This is the most frequently mentioned reaction of parents as well (Knoblock, 1987). Parents may believe that they are the reason of their child's disability. In addition, they may think that they are being punished for past wrongdoings. During the guilt stage, overcompensation which means working too hard to make up for a fault or a defect is a common reaction. Parents try to "make it up" to the child. Nothing is denied that might bring a moment of happiness. The reactions of overcompensation commonly relieve the parents' feeling of guilt. The disability itself becomes more important than the child. During the period of guilt, parents usually do not have any arguments or discussions. In this phase, parents have some obsessive and emotional feelings and they continuously ask the reason of the entire unpleasant event (Webster & Ward, 1993).

Anger is another reaction that a family faces. It is a prevention reaction of the parents' towards the acceptance of the new and unusual situation. Furthermore, it is often described as originally directed toward the disabled child (Zuk, 1962; Pinkerton, 1970 as cited in Knoblock, 1987). Anger can be divided in two ways. The first form which is generally acceptable, often defines anger in terms of fairness and the question "Why me?" is asked by the parents. In the second type, anger is directed toward others, away from the source where it might belong. In order to be hostile to toward someone, a reason must be found to blame that person (Gargiulo, 1985). These kinds of feelings are neither accepted nor found appropriate by the society. As a result of this social norm the parent redirects this anger toward the teacher, doctor, or another professional involved with the child. The reason of this reaction is seen due to parent's displeasure at having an imperfect child. Since it is not possible for the parents to blame the child for having the disability, the focus is transferred to the nearest available professional (Knoblock, 1987).

Shame and embarrassment are other reactions that parents experience. Many parents in social life are proud of their healthy children's performance and success. On the other hand disabled child's parents face social rejection, pity, and ridicule and at the same time they learn to cope with them. It is a fact for some parents of disabled children that the fear of embarrassment occurs because the child's behavior is so unusual and strange that they will not leave the home with the child. Controversially the visit of the people around family would be limited. Hence, social withdrawal may occur (Gargiulo, 1985).

Tertiary phase is the last stage which consists of bargaining, adaptation-reorganization and acceptance- adjustment. In the adjustment process bargaining is one of the final stages. It is the stage that is seen rarely with parents of disabled children so it is personal. Parents of disabled children wish to make a deal with God, science, or anyone who promises to make their child normal in this stage (Gargiulo, 1985).

In the stage of adaptation and reorganization parents are relaxed and quite comfortable. They feel freer to express their feelings. Their self-esteem and confidence in their parenting abilities increase. Their interaction with their child is more positive and constructive. Also, they are more dominant and powerful in dealing with their disabled child and taking responsibilities of the child both physically and emotionally. Their care-taking roles become much better (Gargiulo, 1985).

Acceptance and adjustment is the last phase that parents experience. Most parents who experience the unwanted event of a disabled child try hard to reach for acceptance. This stage is defined as an active process in that parents willingly and consciously show effort, recognize, understand and resolve the situation. However, it is not sure that previous negative feelings are completely resolved. They can occur and happen again. Because of this occurrence parents develop control over obstacles strongly (Gargiulo, 1985).

It is stated that an adjustment is the process in which the acceptance is adjustment. In this phase there is action. It is the action of the individual rather than action done to or for the person by others. It requires change and rearrangement of goal and ambitions. It is a difficult and life long process influenced by attitudes (Gargiulo, 1985).

2.6. Effect of Disabled Child on Mother

Research indicates that having a disabled child brings many challenges in front of the mother such as anxiety, shock, and any other emotional disruptions.

Mak and Ho (2007) conducted a study on caregiver perceptions of Chinese mothers of children with intellectual disability in Hong Kong. Researchers found out that since problem-focused and emotion-focused coping was differentially related to positive and negative perceptions, relatively, relationship-focused coping was significantly related to both types of perceptions. Results of the relationship between positive and negative perceptions showed preliminary support for their orthogonality. Researchers stated that relationship-focused coping was more suitable for understanding caregiver perceptions within collectivistic cultures.

Mu, Kuo and Chang (2005) studied the relationships between boundary ambiguity, which means hesitation in how to behave to the disabled child, coping strategies and depression in mothers caring for children with epilepsy. Findings of the study demonstrated that boundary ambiguity was negatively associated with family coping patterns. Results also indicated that family coping patterns were negatively associated with depression in the mothers.

Eker and Tuzun (2004) examined the quality of life of mothers with children suffering from cerebral palsy compared with those who have children with minor health problems. In this comparative study there were forty mothers with a child suffering from cerebral palsy and 44 mothers with a child suffering from minor health problems. The findings of the study showed that the quality of life scores of mothers were significantly correlated with the severity of a child's motor disability.

Mactavish and Schleien (2004) found that family recreation most often involved small combinations of family members, mostly mothers and their children in physical recreation.

In a previous study by Benn and McColl (2004) that studied parental coping following an acquired brain injury of their child, analyzed the relationship between maternal and paternal coping, and the extent to which social support and family environment affect parental coping. The researchers found parents used coping strategies mostly. When mothers are compared to fathers, mothers had a more extensive repertoire than fathers, and the relationship between maternal and paternal coping seem to be completing. Parental stress of the mothers and fathers of children with an intellectual disability was examined in another recent study (Saloviita, Italinna & Leinonen, 2003). The researchers indicated that parental stress was caused by the negative definition of the situation. The negative definition was related with the behavioral problems of the child in the view of mothers. On the other hand, fathers connected the negative definition with the experienced social acceptance of the child.

A longitudinal study conducted by Kim et al. (2003) with 246 ageing mothers of adults with intellectual disability and 74 mothers of adults with mental illness. The study aimed to identify those changes over time in how mothers cope with the challenges of caring for an adult child with disabilities and the effects of changes in coping on maternal well-being. Results revealed that mothers changed over time in their use of problem-focused and emotion-focused coping strategies. Because mothers tend to exploit emotion-focused coping strategies, both mother groups show decreasing levels of well-being. Indeed, due to the increase in their use of problem-focused coping strategies, the parents of adults with intellectual disability's distress reduced and the quality of the relationship with their adult child improved. Similarly, the parents of adults with mental illness showed improvement in relationship with their adult child since they applied more problem-focused coping strategies. Consequently, it could be said the coping strategies are important in the lives of older mothers of adults with disabilities and have positive effects on the parents' well-being.

Another study searched the interrelationships among psychosocial variables known to affect the health and development of healthy siblings and parents when a child with a chronic illness or disability is a member of the family. It was found that there was a relation between the socioeconomic status and family cohesion in terms of effect on siblings and mothers. It was also pointed out that both socioeconomic status and family cohesion had an affect on the mood of the mother. Furthermore, researchers stated that the healthy sibling's awareness about the illness of her disabled sister or brother, attitude toward the illness, mood, self-esteem, and feelings of social support were interrelated. All these had an affect on the attitude of the healthy child.

Hastings, Allen, McDermott, and Still's (2002) study of mothers of children with intellectual disabilities reported that mothers tend to perceive the child as a source of happiness and fulfillment and as a source of strength and family closeness. Also, all these terms were positively related with reconstructing coping strategies as reported by the mothers. Mothers' perceptions of the child as a source of personal growth and maturity were also positively associated with reframing coping strategies, the helpfulness and usefulness of support from family and friends, and the caregiving demand.

Lam and Mackenzie's (2002) study on Chinese mothers with children with Down syndrome stated that the types of stressors changed over time according to the child's age, and coping strategies varied accordingly. The coping strategies that mothers often used were avoidance, self-reliance, and search for social support.

2.7. Effects of Disabled Child on Siblings

The arrival has effects on the other siblings as well as the parents. Similar to parents' reactions towards the disabled member, healthy siblings can also and frequently do experience the same emotions including fear, anger, guilt, and so. Especially when the sibling is younger, it increases the possibility of experiencing more difficult time than their parents in coping with some of these feelings. Because of being less mature, they may confuse concepts, and misunderstand situations and terms. Additionally, the lack of interest of his/her parents may result in stress in the sibling. Despite the fact that young children may have an uncertain sense that their siblings with disabilities are different; they may still have misconceptions about the nature of their siblings' conditions, especially regarding what caused them (Culatta & Tompkins, 1999).

Cate and Loots (2000) discovered that siblings had difficulties in undertaking activities and in communicating with their brother or sister with a disability. Researchers reported that most siblings worried about the future and the health of their brother or sister with a disability. Nevertheless, in the relationship of siblings with their parents, siblings expressed open communication and trust. Also, siblings stated that their parents tried to treat all children equally, although parents were not always successful in doing so.

Siblings have an important contribution in the functioning of other children in the family. Nixon and Cummings (1999) conducted a study examining sibling disability and children's reactivity to conflicts involving family members. The findings suggested that although it was observed rarely, siblings may significantly affect families in that when the family mostly took care for other disabled children's functioning. It was also identified that children with a disabled sibling and nondisabled siblings responded to a series of arguments involving other family members. Nixon and Cummings (1999) stated that having a disabled sibling increased the sensitivity of everyday family stresses, including more emotional distress, more expected involvement, perceived threat, and personal responsibility, and more active coping strategies. It was also noted that children with disabled siblings have more adjustment problems.

Sibling relationships and parent stress in families of children with and without learning disabilities were studied by Lardieri, Blacher, and Swanson (2000). The results of the study revealed that if the child with learning disabilities had behavior problems, the stress of the sibling increased. Moreover, Williams et al. (2002) stated that the interrelationships among psychosocial variables affected the health and development of healthy siblings and parents when a child with a chronic illness or disability is a member of the family.

When the siblings get older, their thoughts change in that they become more focused on how society views them and their siblings who are disabled. Hence, they may experience a difficult period. They may worry about rejection by peers (Culatta & Tompkins, 1999). Cate and Loots (2000) revealed that siblings became extremely annoyed and distressed due to the clumsy reactions of strangers. On the other side, it was reported that healthy siblings who have a disabled sister or brother did not face with problems in the relationship with friends often.

There are various variables that affect sibling adjustment as birth order, gender, and age differences between siblings (Berry & Hardman, 1998 as cited in Culatta & Tompkins, 1999). For example, a healthy older sister may have a negative attitude especially when she becomes adult since her parents expect from her to share child-care responsibilities. Besides this, siblings of the same gender and siblings who are close in age are more likely to experience conflicts. When siblings are adults, women show more favorable attachments than men to their sibling with a disability. In addition to this, adults who are the same gender as their sibling with a disability experience more favorable emotional responses (Orsmond & Seltzer, 2000 as cited in Culatta & Tompkins, 1999).

Like other family members siblings can adapt well or poorly to the presence of a disabled sister or brother and disability itself. Recent studies pointed out that some siblings have trouble adjusting, some have no trouble adjusting, and some actually appear to benefit from the experience. Like parents, however, siblings of children with disabilities are at a greater risk than siblings of nondisabled children to have difficulties in adjustment. In all, positive and constitutive relations may exist between the sibling and his/her disabled sister or brother.

Rivers and Stoneman (2003) conducted a study on sibling relationships in 50 families with a child with autism in light of the family systems theory. They found that although parents were somewhat less positive about the sibling relationship than were the siblings themselves, typically developing siblings expressed satisfaction with their sibling relationships.

In another study it was stated that the brothers and sisters generally did not experience many significant problems in terms of having a disabled sibling.

However, a minority of the children did experience problems for which they needed help with their disabled sibling. Moreover, healthy siblings had joys as well as problems with a disabled member in the family (Cate & Loots, 2000 as cited in Culatta & Tompkins, 1999).

2.8. Effect of Disabled Child on Total Family System

A number of studies showed that disability affects the family system, interactions among family members and some variables including family size, financial support, and family life cycle. These all have an affect on the disabled individual as well.

One of the studies conducted analyzed three case studies portraying the attitudes and reactions of Israeli parents towards their deformed children. The research method employed was participant observation in homes, combined with in-depth interviews. It was found that parents tended to isolate their handicapped children from family territories in those contexts in which the child was denied as a `non-person'. This pattern was not affected by the parents' socioeconomic status, or by their ethnic and religious background (Weiss, 1997).

Ryan, Campbell, Rigby, Germon, Chan, and Hubley (2006) stated that children with physical disabilities generally require more care, attention and direct supervision than children without disabilities. As a result of this parents and other family members experience poor psychological and physical health states.

Pakenham, and Bursnall (2006) discovered that compared with children of 'healthy' parents, children of a parent with multiple sclerosis reported greater family responsibilities, less reliance on problem solving and seeking social support coping, and lower life satisfaction and positive affect.

Oelofsen, and Richardson (2006) examined the relationships between parental stress, sense of coherence, social support, and health in parents of preschool children with and without developmental disability. The relationship of the sense of coherence construct to parental adjustment was studied as well. Results showed that mothers and fathers of children with developmental disability have high levels of parenting stress. Also, Parents of children with developmental disability demonstrated higher levels of parenting stress, and a weaker sense of coherence. Besides, mothers of children with developmental disability noted that they had poorer health, higher levels of parenting stress, and a weaker sense of coherence than their partners. On the other hand, it was pointed out that there were no significant differences in reported health, parenting stress, or sense of coherence between parents of children without developmental disability. The results of this study supported previous findings on high levels of parental stress in parents of preschool children with developmental disability (Oelofsen & Richardson, 2006).

In a previous study, Stoneman and Gavidia-Payne (2006) investigated 67 families of young children with disabilities. A family systems framework was used to examine associations between stressors/hassles, problem-focused coping, and marital adjustment. The results of the study indicated that most of the couples were experiencing average to above average marital adjustment. Additionally, as daily stress or hassles were higher, husbands and wives viewed their marriages more negatively. However, fathers who employed more problem-focused coping strategies, had more positive attitude about their marriages. Also, it was reported that wives had higher marital adjustment when their husbands employed more problem-focused coping strategies.

In 2006, Blacher and McIntyre studied the behavior problems and adaptive behavior of low functioning young adults, and well-being of their families, varied by diagnostic syndrome including intellectual disability, cerebral palsy, down syndrome, and autism. The findings of the study demonstrated that behavior disorders and maternal well-being of the couples have the same pattern across disability syndromes. Among the entire syndromes, autism was associated with the highest scores in multiple behavior problem areas as well as maternal reports of lower well-being. Whereas Down syndrome was associated with the lowest behavior problem scores, it was associated with the highest maternal well-being. Blacher and McIntyre (2006) expressed that caregivers of young adults with autism report more maladaptive behaviour problems and lower personal well-being, or stress, relative to other diagnostic groups, regardless of the cultural group.

Bailey, Hebbeler, Spiker, Scarborough, Mallik and Nelson (2005) examined family outcomes at the end of early intervention near the child's third birthday. The results of the study revealed that at the end of early intervention, most parents felt competent in caring for their children, supporting their child with services, and gaining access to formal and informal supports. The findings stated that the families were generally optimistic about the future and most of the parents believed that their family was better off as a result of early intervention. On the other side, parents were quite less positive in their perceived ability to deal with their child's behavior problems and in gaining access to community resources.

Stated by Bailey et al. (2005) early intervention provides important support for families of young children with disabilities. Additionally, early identification and efficient directions are important so that maximum benefit can be realized for children with disabilities and their families.

Davies and Hall (2005) indicated that having a disabled child is a major cause of stress and has an impact on the health and well-being of the entire family. The family affected by the disabled children in not knowing how to cope with the issue of disability and in which ways they could help the disabled member within the family.

Some of the previous studies pointed out that parents react intensely to the initial diagnosis of their child's disability. Learning of the child’s disability results in the mother experiencing stress (Poehlmann, Clements, Abbeduto, & Farsad, 2005).

In a study on mothers whose adolescent or young adult was diagnosed with Down syndrome or fragile X syndrome it was revealed that although different patterns emerged for each syndrome group, most families experienced upset and resilience in their reactions to the diagnosis. Furthermore, maternal descriptions emphasized positive attributes that contributed to family well-being and behavioral challenges that were a source of family stress (Poehlmann, Clements, Abbeduto, & Farsad, 2005).

Warfield (2005) conducted a study on family and work predictors of parenting role stress among two-earner families of children with disabilities in terms of some variables. The findings showed that there was maternal and paternal parenting role stress in both common and unique predictors. Furthermore, having fewer children in the family predicted less stress for both parents. The results also demonstrated that household income and an interaction between child behavior problems and work interest were significant predictors of maternal parenting role stress. However, it was found that greater difficulty in finding reliable child care predicted higher levels of parenting role stress for fathers, but not mothers.

The effect of coping style and family functioning on children’s adjustment to sickle cell disease was studied by Lutz, Barakat, Smith-Whitley and Ohene-Frempong (2004). Results signified that disability stress did not mediate the relation between disease severity and child adjustment. Another finding was that the severity of medical condition and medical stress did not predict adjustment. Child gender and child age predicted family functioning and child adjustment to sickle cell disease. Additionally, Lutz et al. (2004) stated that child or parent coping strategies did not reduce the intensity of the association of disability stress and child adjustment.

McNeill (2004) investigated the experience of fathers who have a child with juvenile rheumatoid arthritis. Researchers found that fathers were profoundly affected from their child's condition. During periods of high stress fathers were reported to be stronger.

Mactavish, and Schleien (2004) examined the nature and benefits of, and constraints to, family recreation in families that included children with developmental disability. It was stated that family recreation most often involved small combinations of family members, mostly mothers and their children in physical recreation. Besides, it was seen from the parents that these interactions are beneficial for enhancing family relationships and providing children, particularly those with a disability. Moreover, these interactions gave families various opportunities for skill and self development within an accepting and supportive environment. However, findings noted that there were difficulties in coordinating schedules of family members, finding activities to accommodate to the wide age and skill ranges, planning demands, and limitations in marketing and promotional materials in relation to the family as a whole and the children with developmental disability.

Rivers and Stoneman (2003) conducted a study on sibling relationships in 50 families with a child with autism in light of the family systems theory. They found that although parents were somewhat less positive about the sibling relationship than were the siblings themselves, typically developing siblings expressed satisfaction with their sibling relationships. The results also emphasized the importance of considering family context as a contributor to the quality of the sibling relationship.

Another study searched the interrelationships among psychosocial variables known to affect the health and development of healthy siblings and parents when a child with a chronic illness or disability is a member of the family. It was found that there was a relation between the socioeconomic status and family cohesion in terms of its effects on siblings and mothers. It was also pointed out that both socioeconomic status and family cohesion had an affect on the mood of the mother. Furthermore, researchers stated that the healthy sibling's knowledge about the illness of the brother or sister, attitude toward the illness, mood, self-esteem, and feelings of social support were interrelated and related to the behavior of the well sibling (Williams, Williams, Graff, Hanson, Stanton, Hafeman, Liebergen, Leuenberg, Setter, Ridder, Curry, Barnard & Sanders, 2002).

Trute and Hiebert-Murphy (2002) studied family adjustment to childhood developmental disability. They reported that parenting stress of mothers and fathers are affected by marital adjustment and level of disability in a child. The severity of disability of the children affect the marital adjustment in that parents have difficulty in managing the delivery of the responsibilities and care taking roles.

Lustig (2002) conducted a study on families with a child with a disability. The researcher found that the disabled member within the family system had an affect on families’ problem solving, coping strategies, family adjustment and relationship among them.

Taanila, Syrjala, Kokkonen, and Jarvelin’s (2002) study conducted with parents with physically and/or intellectually disabled children reported that half of the families who participated in the study seemed to have found successful ways of coping. On the contrary, another half had major problems. It was reported that parents' initial experiences, personal characteristics, effects of the child's disability on family life, acting in everyday life and social support were domains in which the high- and low-coping families were found to differ the most from each other.

Tilford, Robbins, and Hobbs’s (2001) findings showed that birth defects require considerable costs on both families and society because of medical, developmental, and special education needs. They also noted that caring for children with birth defects affect caregiver time and impact the family.

According to Grant and Whittell (2000) families with children and adults with intellectual disabilities found coping strategies useful. Also, it was found that coping strategies varied according to gender, life stage and family structure.

2.9. Related Research Made in Turkey

In Turkey researchers conducted various research on disabled children, parents and family of disabled children, educational needs of disabled children and intervention services for these children and for the parents. Most of these used quantitative research designs, and especially employed surveys. There is a lack of studies that examines disability and disability- related concepts. The following studies mostly investigated parental stress, psychological well–being of the parents and the experience of the parents and families face to face with the condition of the disability.

A study conducted by İçöz and Baran (2002) examines the anxiety levels of mothers in families that include a mentally handicapped individual. The study was conducted with mothers of 54 handicapped children with Down syndrome or another form of mental handicap who were attending special education institutions. The results of the study revealed that, mother's degree of anxiety varies according to the mother's age, the date of the first diagnosis and the age of the handicapped child.

Acoording to Şahin and Mağden (2004) it is possible to increase the number of ways to find solutions to the problems of mothers and the other family members having exceptional children by providing psychological and educational consultancy. It is possible to make mothers adopt a more positive attitude towards their exceptional children. As a result, the communication between the mother and their children can be enhanced. In addition, the self confidence of these children can be increased. In their study with families of exceptional children, mothers participation in children's activities which support their social development were not different from that of the children showing normal growing signs at the same age. On the other hand, the number of the social activities that their children participated in was less than that of the normally growing children, at the same age. Moreover, it was reported that the mothers preferred their children's behavior to be in harmony with the society and dignified, but they worried about their children's "future" and the "unsuccessfulness at school". The researchers indicated that there was a positive relation between the behavior of the exceptional children and their diagnosis and a significant relationship was determined between the attitudes of mothers and the social problems of their children.

In a study made by Duygun and Sezgin (2003), researchers found that there were significant differences between the emotional burnout levels and submissive coping style levels of the mothers of mentally handicapped children and mothers of healthy children. The mothers of mentally handicapped children had higher scores than the mothers of the healthy children in terms of emotional burnout levels and submissive coping style levels.

Bilal, and Dağ (2005) conducted a study examining the relationship between the level of stress and the coping styles and locus of control beliefs in mothers who have children with mild mental disability and the mothers with normal developing children. The results of the study showed that the mothers who had mentally handicapped children experienced more cognitive-affective stress symptoms. It was also found that the self-confidence and the submissive/self blamed coping styles predicted the total stress level that the mothers experienced.

Şahin’s (2006) findings showed that there was a relation between the mental disabled children's intelligence level and parents' training level in that as the parents' training level decreased, children's intelligence level decreased as well. The intensity, interest and the care of the parents on the training of the disabled child is important.

Ahmetoğlu and Aral (2005) in a study of 100 mothers of mentally and Physically Handicapped Children examined the anxiety level of mothers and whether the age of the handicapped child and the date of first diagnosis caused a difference in the level of anxiety. The researchers discovered that anxiety level of mothers of mentally retarded children was significantly different according to the age of the children and the date of first diagnosis.

In a study undertaken by Sunal and Çam (2005), researchers found that among fifty eight hearing-impaired children, 16% of the hearing-impaired children had neurotic problems whereas 29% had behavioral problems. Also, some of them had some psychological problems as well. Additionally, they noted that there was a significant relation between the age that the families first recognized the hearing-impairment and the average point of behavior. The children whose families first noticed their hearing-impairment at 12-24 months of age had a higher average of behavior points than the ones noticed at 24 months of age and older. The results also indicated that there was a relation between the average total neurotic point and the living place of their families and the communication styles. The average neurotic points of children living in countries and communicating with sign language, was found to be higher. The researchers reported that the average psychological problem point of these children is lower when they can communicate more effectively and have a better school performance. Furthermore, they stated the importance of earlier detection and diagnosis of hearing-impairment for the psychological health of these children.

In Turkey, the demographic data of 1167 patients who were examined and monitored in the clinic center between January 1995 and December 2003 were evaluated in the Edirne district. The results demonstrated that the majority of applications were made between 1997 and 1998. Of 1167 patients, there were 476 females (40.8%) and 691 males (59.2%) with a mean age of 4.22Â±4.00 years. Distributions of diagnoses were as follows: 47.1% (n=550) were mentally handicapped; cerebral palsy, 37.5% (n=438); autism, 2.7% (n=32); Down syndrome, 4.2% (n=49); and developmental retardation, 8.4% (n=98). Moreover, it was noted that only 14% of all the cases were found to follow the education program in the center (Ahmetoğlu, Canarslan, Vatansever, & Kutlu, 2005).

Uğuz, Toros, İnanç, and Çolakkadıoğlu (2004) conducted a study on sociodemographic properties of handicapped children and compared their mother's depression, anxiety and stress levels with that of mothers with healthy children. The findings revealed that mothers of handicapped children had a greater level of depression, anxiety and stress than mothers of healthy children. The researchers suggested that mothers of handicapped children should be given regular psychological support.

Özşenol, Işıkhan, Ünay, Aydın, Akın and Gökçay (2003) stated that families with handicapped children may have many problems. In their study, evaluating the variables affecting the family function of families with handicapped children, they reported that mothers blame themselves for the reason of their child's or children's disability. This affected the general function, roles and emotional reactions of the mothers. Moreover, the fathers were affected from this in terms of general function, emotional reaction and communication. The researchers stated that it is essential to determine and to solve the problems of the families with handicapped children.

Özşenol, Ünay, Aydın, Akın and Gökçay (2002) expressed that a handicap is an entity which caused by many psycho-social problems. The researchers evaluated psychological status and expectations of parents of motor and mentally handicapped children. The results revealed that demographical factors may affect psychological status and expectations of parents. The parents of disabled children have great expectations about their children's status. Furthermore, high scores of emotional burnout were identified in these parents.

Sucuoğlu (2001) studies the differences of interactional behaviors between mothers and children with mental retardation and mothers and non-retarded children. The data was collected from 15 mothers and children with developmental disability and 15 mothers and typically developing children. The researcher identified that there were no statistically significant differences between interactional behaviors of the two groups of the mothers in the teaching, controlling and goal settings behaviors. Another finding of the study was that mothers and children demonstrated lack of behaviors for interaction. It was also found that children with and without mental retardation were different on play, and acquiescence.

Özer and Mangır (1997) conducted a study examining the characteristics of educable mentally retarded children who attended vocational schools and their parents and thus to contribute to the planning of education. The results demonstrated that the families mostly come from low socio-economic and cultural levels and seventy five percent of the parents who had participated in the study realized their children's situation when the children were below six years old; however, almost all the children received no education in the preschool period. From the collected data the parents have stated the problems their children face in daily life, like the problem of adaptation to sociological environment and making friends, inability to count money, and inadequateness in expressing their ideas and feelings. The results also indicated that behaviors such as telling lies, biting nails and enuresis nocturnal were identified in children and they were mostly nervous, impatient and conciliatory as reported by the parents. Furthermore, as indicated by the parents, their children mostly liked sports, repairing things and handcrafts.

In Turkey studies have mainly been conducted on the mothers' or the parents' emotional situation, their stress level and anxiety about having a disabled child or children. Also the equality of the relation and the interaction between mothers and the disabled children were studied. The importance of early detection and diagnosis has been emphasized in the studies as well. The adaptation problem of families of disabled children within the society and their anxiety about future and expectation of the parents from their disabled children were some subjects examined by previous research. However, there is a lack of studies that focus on a specific situation about the disabled children and the mother. Also the importance of the father and the care taking role of the father was underestimated and has not been examined profoundly. Moreover, there are no longitudinal studies about the disabled children and their families in Turkey.

CHAPTER III

METHODOLOGY

In this chapter the selection of the researcher design and the reasons of this selection related with the purpose of the study were discussed. In addition to this, participants of the study, data collection, and data analysis processes are given.

3.1. Research Design

Qualitative research design has become an established tradition research method in both the social and behavioral sciences. Qualitative inquiry includes a number of approaches which are biography, phenomenology, grounded theory, case studies, and ethnography (Fraenkel & Wallen, 2003). Creswell (1998) describes qualitative research as:

> Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher build complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting. (p. 15)

Quality of a particular activity may be interesting for many researchers than the occurrence or evaluation of it. Qualitative research study, examine or investigates the quality of relationships, activities, situations, or materials (Fraenkel & Wallen, 2003).

Qualitative inquiry was defined by authors by comparing it to quantitative inquiry. Generally, researchers who conduct quantitative studies work with a few variables and many cases, however, researchers who conduct qualitative researchers depend on a few cases and many variables (Creswell, 1998). The qualitative method is different from the quantitative method in that the qualitative method is viewed from multiple perspectives rather than from a single point of view. The qualitative research may deal with many roles to complete the task worked on. Also, it provides an in depth understanding of the phenomenon the researcher studies. The qualitative researcher approaches the world with a distinct set of ideas or framework that specifies a set of questions which are taken and analyzed and written about (Fraenkel & Wallen, 2003).

In addition to the given information above unlike quantitative studies the steps in qualitative research are not clear. In qualitative studies, it is expected from the researcher to identify the particular phenomenon that he or she wants to explore before hand. Furthermore, in most of qualitative research, the sample is a purposive sample. It means that researchers choose a sample they think will provide the best understanding of the phenomenon. Additionally, Fraenkel and Wallen (2003) state, “A typical qualitative study may begin with few, if any, hypotheses being posed by the researcher at the start, but with several being formulated, reconsidered, dropped, and modified as the study proceeds.” (p. 435). In a qualitative research study the collection of the data is in progress. Fraenkel and Wallen (2003) states, “The researcher is continually observing people, events, and occurrences, often supplementing his or her observations with in-depth interviews of selected participants and the examination of various documents and records relevant to the phenomenon of interest.” (p. 435). Analyzing the data in a qualitative study is another subject. It includes analyzing and synthesizing the information. This information comes from the researcher's various sources from his observations and investigation about the data. Data analysis in qualitative research, however, depends mostly on description rather than on inferences of the researcher. In qualitative research, the conclusions are generally left to the end of the research. Furthermore, qualitative researchers tend to formulate their interpretations as they go along (Fraenkel & Wallen, 2003).

Case studies have become one of the most common ways to conduct qualitative studies (Fraenkel & Wallen, 2003). Some of the researchers may consider "the case" an object of study (Stake, 1995 as cited in Creswell, 1998), and others may believe it to be a methodology (e.g., Merriam, 1988 as cited in Creswell, 1998). A case study is defined as; "an exploration of a "bounded system" or a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context." (Creswell, 1998, p.61). In addition to this, a case study is seen by some researchers as not only an individual or situation that can easily be identified, but also as an event, an activity, or an ongoing process. Mainly there are three types of case studies (Fraenkel & Wallen, 2003). One of them is the intrinsic case study, in which the researcher is initially interested in understanding a specific individual or situation. The aim of the researcher is to understand the case multi dimensionally. If a researcher wants to know about the phenomenon in depth, they often use exploratory research which directs him or her to an intrinsic case study. Another kind of case study is an instrumental case study in which "a researcher is interested in understanding something, more than just a particular case" (Fraenkel & Wallen, 2003). In an instrumental case study, the researcher is interested in studying the particular case only as a means to some larger goal. The other one is the multiple or collective case study. In a multiple or collective case study the researcher investigates multiple cases at the same time as part of one overall study (Fraenkel & Wallen, 2003). This means that there is more than one case in the study (Stake, 1995 as cited in Creswell, 1998).

Furthermore, there are some differences between multiple or single case designs. They both have some advantages and disadvantages (Fraenkel & Wallen, 2003). In multiple-case studies the results are often considered to be more convincing and to make a valid generalization is somehow accessible in these studies. From the other point of view, in single-case design research certain types of cases such as the rare case, the critical case for testing a theory, or the case that allows a researcher to observe a phenomenon previously unreachable to scientific study, it is difficult to make generalizations (Fraenkel & Wallen, 2003).Moreover, when compared with single design, multiple-case studies often need comprehensive resources and time (Creswell, 1998).

In case studies, data are collected by many instruments such as observations, interviews, audio-visual material, and documents and reports. “The context of the case involves situating the case within its setting, which may be a physical setting or the social, historical, and/ or economic setting for the case” (Creswell, 1998, p. 61). After the collection of the data by the means of these data collection instruments, researcher describes the case by analyzing the themes or issues and provides interpretations or assertions about the case (Stake, 1995 as cited in Creswell, 1998).

Moreover, researchers use theory in case studies in different ways (Fraenkel & Wallen, 2003) in that some simply describe cases, and others give information more analytical in nature and display cross-case or inter-site comparisons (Creswell, 1998). The purpose of the case studies in general certainly designs the larger structure of the written narrative. After data collection, analysis, and formation of a theoretical model, the turn comes to the advancing a "theory-after" perspective which means the introduction of theoretical perspectives of psychosocial and organizational perspectives to compare and contrast the case with the theoretical model the researcher used (Creswell, 1998).

At last, Fraenkel and Wallen (2003) indicated “the researcher develops naturalistic generalizations from analyzing the data, generalizations that people can learn from the case either for themselves or for applying it to a population of cases.” (p. 440). This enables the readers to look at the event from a wider perspective.

I conducted my study by using a qualitative process of inquiry. Among qualitative research designs the single-case design was used in my study. I choose this design for several reasons. Firstly, the main focus of my study is to identify and examine the coping strategies of a mother who is faced with the challenge and multitude of difficulties and decisions involved in caring for multi-disabled children. Having more than one child with disability especially diagnosed as multi-disability is rare case. This unique and valuable subject should be worked with deeply and intensively. My main goal was to look deeply into the experience of the mother. For this purpose, the case study design would provide a deep understating of the situation. Additionally, it is much more appropriate than any other designs in order to reach this aim since the intrinsic case study (single case designs) (Fraenkel & Wallen, 2003) allows one in-depth scrutiny of a phenomenon (Creswell, 1998).

Secondly, the study utilized a qualitative research with case study design since there is lack of a wide range of previous research in this area with this design.

Another reason why a qualitative inquiry was selected for this study is that it permits an investigative intimacy with the participant. Because the case and the participant of the study is a "mother" and the aim of the study is to explore how she copes with this issue in a family setting and what kinds of coping strategies she uses to manage difficulties. Besides, a qualitative inquiry was employed to understand her expectations during pregnancy and her feelings after the childbirth, her children's early years, diagnosis, and her current thoughts and feelings about mothering children with multi-disability. To reach this aim; in-depth interviews, which are one of the most important of data collection components of a case design, were used. Through detailed and in depth interviews patterns will be created and themes will be identified and this process allows a close relationship between the researcher and the informant to flourish. This can only happen as Fraenkel and Wallen (2003) stated "The researcher is continually observing people, events, and occurrences, often supplementing his or her observations with in-depth interviews of selected participants and the examination of various documents and records relevant to the phenomenon of interest" (p. 435) in qualitative inquiry especially in case studies. This face to face in-depth interviews used in case designs will provide some useful information that will help in explaining the mother's role in the link between the disabilities and experiences of rearing disabled children and her struggle within family context.

By utilizing the qualitative method of case study analyses, the aim is to explore the feeling, thoughts and ideas of the mother by the means of interviews, look at the strategies that a mother has developed to cope with the disability and explore how this may impact the mother as well as the family.

The final reason for choosing a qualitative study is that it gives deep understanding of the event from many dimensions. This deep examination of the subject has social significance since society may understand the importance such a case and work with it more sensitively. This important subject cannot be measured, but it can be explored using a qualitative design.

3.2. The Case

In this part I explain how I reached the participant of my study, followed by information about the mother, her disabled children, her healthy child, husband, and extended family. The aim of giving information about each family member individually is to understand the family dynamic as a whole and in this dynamic the role and place of the mother. Additionally, to understand this dynamic and the relation and interaction between the mother and the other family members, I focused on the Family Systems Theory. It is important to give information not only about the mother in detail but also the other family members. This will provide us with a wider perspective to perceive and understand the experience of the mother with her disabled children. All the names used in this study are pseudonyms.

I have been working in the field of special education for approximately five years. I met the mother in my study in the special education and rehabilitation center where I work. I gave individualized education to her youngest multi-disabled child, Melek, for about two months. In this period of time, I established a relation with the mother. Having more than one child with multi-disability is a sensitive and an uncommon event. This unusual case attracted my attention; hence, I decided that I would like to understand the issue profoundly and work on it through a structured research.

The relationship between the mother and me was more formal at the beginning of our meeting. After each session, I provided the mother information about the quality of the session, an evaluation of the child's communication with me, information on how the activity went and how the child responded to the activity. Finally I gave information about the overall evaluation of the session to the mother. Later I assigned some homework related with our activity with the child. This routine communication among me, the mother and the child prepared a base for me to work with the mother and made her comfortable, relaxed and trustful enough to participate the study.

I talked about the significance and the purpose of the study with the mother. I gave information about how valuable this study was for me and would be for the society. Later, I stated the contribution of the study for the literature and the practice. All these aspects made the mother accept to participate to the study voluntarily and willingly. She expressed her feelings as "I will be very happy to share my experience with you. If my experience will be useful for other people, I would feel happy, really."

Considering how I reached the mother, it can be conclude that this study employs both purposive and convenient sampling. It was purposive since the existence of two multi-disabled children in the family was an unusual event. It was convenient since the mother was taking education for her disabled children from the special education and rehabilitation center that I was working at. Thus, it was easy for me to reach and contact the mother.

The case of current study is a "mother" whose name is Fatma. Fatma is quite a tall woman in her early forties. She had a smile on her face frequently. She seemed a bit excited at the beginning of the interview, but later she was quite relaxed and answered the questions frankly, fluently, and extensively.

3.2.1. Cultural Background of the Mother

Fatma is from Diyarbakır, Turkey. Both her mother and father are also from Diyarbakır. Her father was a teacher and her mother is a housewife. They lived in the center of Diyarbakır. According to the mother, the father did not use very strict home management styles. However, she only attended secondary school and did not go to high school. It was stated to the mother that the high school was unnecessary for her and her prospective husband would not let her receive higher education. The husband would ask her to stay at home and take care of the children and the home. Thus, when Fatma was 16, she got married. The women are obedient in this culture towards their husband and extended family members. The mother has the duty as taking care of the all family members and it is expected from the mother to deliver a male baby. The mother had to continuously obey and take the approval of the extended family. The mother and father-in-law had a dominant and controlling management on their daughter-in-law.

The mother belongs to a family coming from a middle socio-economic status. Her husband works in Ministry of Education. He worked as an English teacher in government schools before he stared to work in the Ministry of Education. He is in his late forties. He also comes from an eastern culture. He is also from Diyarbakır. He expects his wife, the mother, to be a competent house wife and obedient towards him and his parents as the mother stated.

The extended family is quiet structured. The grand mother is in her early sixties and the grandfather is in his late sixties. They have an eastern feature of living style. They have a close relationship with their children especially the male ones. They are in expectation of living their old ages next to their sons not their daughters. According to them, the one who looks after the mother and the father is the son not the daughter. Hence, it can be inferred that the mother's in-laws expected Fatma to look after them as she was the wife of their son.

3.2.2. The Mother, Multi-disabled Children and Health Child

Fatma, the mother, is a full-time, at home mother of three children. Her oldest daughter, Sevgi is 23 years old and has multi-disabilities including a hearing impairment, cerebral palsy and mental retardation. Her second child, Ayşe, is 18 years old and the healthy member of the family and her youngest child Melek is 14 years old. Like her oldest sister, Melek has multi-disabilities including hearing impairment, cerebral palsy and mental retardation. Mrs. Fatma had her first delivery when she was 18.

Mrs. Fatma had normal deliveries and initially reached all her developmental milestones during the pregnancy. However, she delivered her first baby at home and the others in hospital. She reported the reasons for the occurrence of the disabilities with her disabled children as having a stomach ache and because of that she had to take a painkiller and experiencing a tonsil inflammation she had to be injected for a period of time which crossed at the same time with the fist days of the last pregnancy. Also, as she stated she received dental treatment because of a toothache.

Fatma delivered her first child, Sevgi, when she was eighteen. In the first months after the delivery, the parents did not recognize any difference with the baby. Nevertheless, Sevgi cried frequently and suffered from colic. When Sevgi was seven months old, the mother recognized that the baby was like dough, having uncommonly very soft muscles. Later, she noticed that the baby also did not have power to keep her neck straight. Finally, unusual development of the baby was directly identified by the mother-in-law of Fatma during a visit to Fatma. Following the examination of doctors, Sevgi was diagnosed as cerebral palsy. Unlike the time of diagnosis of cerebral palsy, Sevgi's hearing impairment was recognized very late, after the birth of Fatma's other two daughters. Hence, it was only at 10 years old that Fatma recognized that there was something wrong with Sevgi's speaking. Later the doctors diagnosed her with having hearing impairment and mental retardation. The reason of the disabilities noted by the doctors was the delivery complication. They stated that the delivery occurred at home with a lack of medical materials. However, until the recognition of her disabilities, Fatma explained that Sevgi had difficulties as early as preschool because of her disabilities especially her hearing impairment. At age seven she had difficulties that were perceived to be behavioral problems. Furthermore, Fatma remembered this as a difficult time when Sevgi tried to communicate with her peers.

Her second child Ayşe was a normally developed child. She was an expected child as indicated by the mother. Fatma did not feel anxious during the pregnancy about having another disabled child since doctors reported the disability of the first baby to be caused by the home delivery. When Sevgi was three years old, Ayşe was born. Unlike Sevgi, Ayşe was a quiet and easy going baby. She could walk and talk when she was nine months. Ayşe learned how to read and write while the mother was trying to teach reading and writing to Sevgi. During the childhood of Ayşe, she helped her mother and took some small responsibilities of her disabled sisters. In this period of time she felt that she was forgotten by her mother. She felt lack of interest and care from her mother. Later in her life Ayşe shared her feelings with her mother. The mother had not been aware that she had treated Ayşe insufficiently in terms of love and affection. During high school, Ayşe's daily routine would consist of studying her lessons, helping her mother with both the housework and her disabled siblings. The mother was helping her disabled siblings in their education, dressing, and eating. Apart from this, Ayşe was a social young girl. She had close communication with her classmates. She occasionally met with her friends and participated in some social activities such as going to the cinema, and shopping. She also took her friends home and introduced her disabled sisters to her friends. As the mother stated, Sevgi and Melek enjoyed being introduced to Ayşe's friends. Even Ayşe friends' brought some presents for her disabled sisters from time to time. Thus, Ayşe got used to living with her disabled sisters. She accepted and adapted to them. She was also aware of being a sister of two disabled siblings. After Ayşe finished high school, she did not prefer to apply for higher education. She decided that she would like to extend her knowledge on the subject of religion. Her parents respected her decision. Today, she continues to meet her friends and when necessary helps her mother in daily house work and deals with her disabled sisters' needs.

When Ayşe was six years old, Fatma delivered her youngest daughter, Melek. According to Fatma, she had used injections because of a tonsil inflammation without being aware that she was pregnant. However, after doctors' decision that there was nothing to be afraid of related to the baby's health, they became relaxed. Most of her pregnancy period passed well except for a tooth ache. Because of a strong tooth ache she had to have an intervention (pulling out a tooth). Unlike Sevgi, it was Fatma's grandmother who realized that there was something wrong with Sevgi's muscles as she was washing Sevgi in her first days. Then they immediately went to a hospital for a doctor consolidation. And the same diagnosis, cerebral palsy, was given to Melek, too. Her hearing impairment was recognized earlier than Sevgi as well. While she was two and half years old, Mrs. Fatma realized that there was a problem in her hearing. After they went to the hospital, it was understood that Melek could not hear as well. Moreover, the result of the hearing test demonstrated that Melek's hearing impairment level was much higher that her sister Sevgi. A difficult struggle had started again for the mother and the family as a whole again.

Presently, Melek attends a government school for hearing disabled children. She is in the eighth grade. At the same time she attends special education services from a special institution and rehabilitation center for two hours a week after school. Sevgi finished high school at the government school for hearing disabled children. Like Melek, she also attends special education from a special institution and rehabilitation center for two hours a week.

3.3. Data Collection

Detailed, structured, and in depth interviews were conducted to examine the experience of a mother rearing multi-disabled children, and the effects of having more than one child with multi-disabilities including mental disabilities, hearing impairment, and physical disabilities on the mother's psychological well-being. Additionally the interviews were conducted to explore how a mother copes with this issue in a family setting and what kind of coping strategies the mother uses to manage difficulties. In-depth interviews were conducted with the mother, and information was gathered in the areas of daily stress, coping, family reactions and well-being. Family Systems Theory provided the theoretical framework of the study.

The format of the interview was open-ended questions structured around the family systems theory. The interviews also referred to stress factors of the mother in regard to the internal family dynamics and daily living. These stress factors are associated with disability itself, and how it affects the family as a whole. The interaction and communication between the mother and both her disabled children and healthy child was also examined. The participant gave permission for interviews to be audio-taped. The tapes were transcribed.

Four interview sessions were conducted with the participant in two months. Each session lasted approximately one and half hours. The interview questions have structured under four main title; (1) experience of the mother, (2) communications of the mother among her hearty and disabled children, (3) coping and reaction of the society, (4) family members' relations and the family dynamic. After collection of the data, I went through the data analysis and in this period I recognized some missing information. In order to fill these missing parts I contact with the mother and obtain the needed information. Interviews were conducted entirely by the researcher, and the interview location was chosen by the research participant to facilitate her comfort. Two of the interviews were done in the special instruction center where her children attend. The other two were conducted in the mother's home.

Interview questions were left open and general so that they would not influence the participant in any way as well as to gain as much information as possible. In order to conduct the first interview with the mother I called her and tried to find a suitable time and place both for her and me. I asked her to choose the meeting location. The first interview took approximately one and a half hour. In the first interview I asked as related to the personal experience of the mother in having and raring disabled children. The following are examples of questions as; "What were your expectations and feelings before the first childbirth? What changed after that? What were your expectations and feelings before the second childbirth? What changed after that? How does it feel to be a mother of multi-disabled children? In your opinion, what are some of the particularly stressful issues in mothering children with multi-disability?" The first interview took approximately two hours.

I conducted another interview because I need to know much about the communication patterns among the family members and the reactions of them towards disabled children. After that I prepared for the second interview by arranging the questions before meeting the mother. In my second interview with the mother I mainly focused on the family relations a whole and the mother's source materials in orders to look after her disabled children. I asked "How do the multi-disabilities affect your family? Tell me about your relationship with your multi-disabled children? What resources do you presently use to help you with your disabled child/children? (For example, home care assistance, support groups, therapy, counseling, etc.)

In my third interview I focused on "What is the difference between the first child and second child in terms of your feelings? What was the society's reaction to the disability and to your disabled children? And "how did you cope with that issue?" to the mother. This meeting lasted approximately one and a half hour.

In the fourth interview my questions focused more on the family members' relation and the family dynamic since my study is based on the Family Systems Theory. I asked "How was the reaction of the father towards you, and the disabled children? How was the process of acceptance of him? How was the reaction of the healthy child towards the disabled sibling? How was her acceptance process? How was the quality of relationship between the healthy child and the disabled children?" This interview lasted approximately two hours.

During the literature review I came across some important parts and I had a need of asking or adding few questions to my interview questions. At the end of the fourth interview I decided to go through the data and started to analyze. I needed to contact with the mother when some insufficient information appeared during the analyses and to obtain some missing information. With this process, data collection procedure was completed.

At the end of each interview I clustered the related issues that the mother had focused on. I also wrote some notes about my observations and ideas to remember later on.

I used open-ended questions during the interview in order to gain profound information from the mother. From these interviews I come up with some general themes including mothering multi-disabled children, mother acceptance of multi-disabled children, father's reaction to the mother, extended family impact on the mother, the relationship between the mother and disabled children, siblings' relation, coping with disabilities within the society, and quality of support of services and mother anxiety about future by the help of Family Systems Theory.

3.4. Data Analysis

The data of the study were transcribed interviews conducted by the mother. The interviews were transcribed word by word. Data analysis included some ordered steps. In order to analyze the data I collected, first, I attempted to organize what I heard; wrote and read it several times so that I could understand the data deeply. After that I could pass to the next step.

In this step, in order to categorize, synthesize, and search for patterns and interpret data I wrote "memos" (Glesne, 1999, p.131), which means to keep a reflective field log, including my thoughts. The comments and thoughts recorded as field log entries or as memos are links across my data that find their way to "analytic files" (Glesne, 1999, p. 131). These files ensured the data to be stored and organized in the way of my own thoughts. Within these analytic files I classified the responses of the mother into several categories and I put the answers into categories that they related to the most. I also used "direct interpretation which means to look at a single instance and draw meaning from it without looking for multiple instances" (Creswell, 1998, p.154). This process allowed me to combine the data in a more meaningful ways. Besides this, I constructed "patterns" (Creswell, 1998, p.154) and sought similarities between two or more categories. After that stage, titles of themes were created.

While creating the framework for my study, the title and the related themes I benefited from the literature, as well. There are several studies (Dale, Jahoda & Knott, 2006; Leiter, Wyngaarden Krauss, Anderson & Wells, 2004; Gallo & Szychlinski, 2003; Sharpe & Rossiter, 2002) conducted on disabled children and their parents or families. The themes that emerged from my study were generally similar to these studies.

After emerging of the themes and the reporting of the results I made a phone call to the mother and took her approval about the themes and the results related with them.

I constructed "generalizations" (Creswell, 1998, p.154) in the final part of my study. I examined in detailed the themes and later compared and contrasted them with published literature on disabled children and their families.

CHAPTER IV

RESULT

A mother of children with multi disabilities was interviewed for this case study. Each interview was conducted privately with only the mother by the researcher. As a result of the interview, several themes emerged: mothering multi-disabled children, mother acceptance of multi-disabled children, father's reaction to the mother, extended family impact on the mother, the relationship between the mother and disabled children, siblings' relation, coping with disabilities within the society, and quality of support of services and mother anxiety about the future. I aimed to find answers to the following questions:

1. How does having more than one child with multi-disabilities including mental disabilities hearing impairment and physical disabilities affect the mother's psychological well-being in family and social context?

2. What are the mother's perceptions and feelings about having children with multi-disabilities?

3. How does the mother accept her multi-disabled children?

4. To what extent does the mother accept her children's disability?

5. What kind of coping strategies did the mother use to manage difficulties?

4.1. Mothering Multi-Disabled Children

From the perspective of the mother, the story of mothering to multi-disabled children was really very impressive and interesting. From the interview I conducted with the mother, I observed that mother's initial feelings in terms of mothering to disabled children were shock, experience of hesitations and confusion since it was an unexpected situation for her. Such an unwelcome event is something more shocking than simply finding out one has given birth to a girl even though a boy was expected.

It is usual that most of the mothers have some expectations, hopes and a preference about the gender of their babies. The mother in my study also had some hopes like that. When I asked the mother about her expectations and feelings before the birth of her first child, she said "I mostly like baby girls and I wanted to have a daughter. I wanted to plait her hair. I had a dream like that. I don't know why" in other words her expectations like other mothers in general included excitement and happiness.

I asked the mother the following question "How does it feel to mother a multi-disabled child?" She responded to this question in terms of various aspects including instances of confusion, mothering responsibilities, and change of attitude.

First of all it was a confusing situation because the mother did not know where and how to start to care and communicate with the child. She said "It was confusing since I was 18 years old, a very young mother. And I didn't know what mothering is exactly. I didn't know especially how to mother a disabled child."

Another aspect that emerged from the result of the interview was mothering responsibilities. I came up with the fact that mothering multi-disabled children place more responsibilities on the mother:

> I had to carry Sevgi in my arms until she was 8 years olds because she wasn't able to walk properly. She fell from time to time and sometimes

> hit the furniture. I didn’t let her go outside and she was at home with me all the time.

The mothers of normally developed children hold their children approximately till they are two years old and support their initial care at an average level; however, the mother in the study had to hold her child until she became eight and dealt with her personal hygiene such as bathing, toileting, cleaning, long into the lives of the children. Thus, these intensive responsibilities have been experienced by the mother in mothering process so far.

Mothering responsibilities were not only physically but also academic too. She had to spend much more effort to rear the disabled children than the mothers of typically developed children. Another aspect that made this process difficult is the late diagnoses of the disabilities especially the hearing impairment. The mother said as: “having both the help of the teacher and especially mine, Sevgi could learn how to read and write.”

The point that I noted during the interview was the unequal attitude of the mother towards her disabled children and healthy child. She had difficulties in balancing her behaviors:

> When I realized that I was pregnant, I thought I would neglect Sevgi. I became sad for Sevgi. Actually I thought if I had another child, my strains would increase. Would I be able to care for Sevgi, deal with her and so many questions were in my mind at that time.

Although the arrival of a new baby to a family with disabilities is a misfortunate event, this misfortune might change later with the time. Mothering both disabled and healthy child at the same time brings help in responsibilities and support for the mother and disabled children. The mother indicated that:

> Actually my thought about the second child wasn't true. I saw myself very important for Sevgi but a sister for her was more important than me. I noticed that.

Another mothering difficulty is having another multi disabled child. The mother said "I became both happy and sad of having a child. Well, it was very different and strange feeling. You experience both happiness and sadness along with it."

It was gained from the statements of the mother that she had to cope with another disability and experience the same process of rearing a multi-disabled child. She recalled the stages of experiencing a disability in her life again. This made her feel anxious and worry.

In conclusion I could state that the mother relations were confusing and her mothering process contained sadness, pain and struggle, however also enjoyment and happiness. Later in her life an increase was observed in her consciousness, awareness and maturation on her ideas and thoughts. The mother explained this change as differences between the first years of her life with living with her disabled children and now.

4.2. Mother Acceptance of Multi-disabled children

In the man's mind "mother" has a meaning of love and affection. The word "mother" is enough to make a person feel peace in his or her heart. Mother is the person who cares, saves and who gives unrequited love. In my study, the mother is the person who looks after, saves, cares for and supplies the needs for both her disabled children and the healthy child with great affection. After a long journey of struggling with the emotional disturbance of having two multi-disabled children, the mother accepted her children with their appetence and as they are.

At the beginning, as most of the mothers do she had some dreams and hopes about her unborn baby during the pregnancy and even before that time. These dreams and hopes changed having recognizing the impairments in her baby. She expressed her shock as follows: “I was shocked. My whole world collapsed around me. I was now a mother of a disabled child.”

During this suffering process she and her husband visited hospitals many times. Although the health centers that the parents applied to were highly qualified, the doctors over were not able to recognize the other disabilities including hearing impairment and mental retardation in both children. Because of late diagnosis, the mother had to experience the reaction and feeling of shock later in life again and again as each impairment was diagnosed with time.

She experienced the acceptance of disabilities within a process. In this acceptance process, spiritual beliefs and religion came up as an important concept: “I believe in God and respect his decision”. The core issue was the belief of relying on the decision of God which is named as “fate”. Throughout the interview, the mother used some words and expressions which addressed this belief and trust of God. I realized that it was not only the fate which made her tolerate such difficulties with her disabled children, but also her belief that this life included problems and difficulties. It contains an exam and a temporary life. Hence, she believes that God will compensate and reward her and her children in the life with the paradise and of course with a healthy, wealthy and happy life and family in the other life.

Three years after her first child Sevgi was born with multi-disabilities, Ayşe, the healthy sibling, was born. At that time, the mother lived a difficult life. She had many fears about how to look after another while she already had one child with disabilities. However, her negative feelings and desperations changed into positive and hopeful ones. She explains this change in terms of the belief of God. The mother stated the following:

> I always say that My God closed one door for me, but opened another one. Well, he didn't give a difficulty, but he gave me comfort, he helped me. Especially after Sevgi, I thought it will become too difficult but God, for whom I sacrifice myself, he helps me a lot and always cares about me.

Although the doctors told the mother in her last pregnancy that the baby was developing normally and nothing was wrong with the baby, she felt that Melek would be disabled. Also she added:

> Well, I asked myself even I knew that she had been disabled in my stomach, I wouldn't have aborted her. I believe it was my fate to have and live with two disabled children. If I had asked for an abortion, my healthy baby would become disabled. We can't escape from fate. Most of the reason for the children being handicapped is not because of mistakes in delivery, but in fact they have fever or accident. With these consolations, my psychology remained stable.

Having lived for twenty years with her disabled children and disabilities, the mother appears to be in the last stage of the acceptance process. As she stated:

> When looking at the past, I can see my mistakes. I didn't receive any psychological help. I would have liked to receive psychological treatment, but I didn't. To become useful for my disabled children, I should have had the treatment. But I remained psychologically stable. I always see worse ones than my children, and when I see, I say we are fine. I thought like that. I convinced myself like that and I didn't give up.

She gives the impression that she has well-adapted to the condition of living with disabled children. She became completely united with her disabled children. She appears to be confident.

4.3. Father's Reaction to the Mother

As a result of the interview conducted with the mother, it was revealed that there was an immense effect of the father on the mother in acceptance of the disabilities, care giving role, psychological well-being and financial support. Among all those issues the emotional support of the father was the most initial and essential one. As the mother stated "At the end he accepted the disabilities and stopped blaming me. That time I really felt very well."

In such a critical situation the emotional support that comes from people is the mother's initial wish since she was in shock and discomfort and her psychological well-being was open to any vulnerabilities that could come from outside especially from the husband who was her life partner.

The reaction of the father towards his first baby's disability and his wife was not very disruptive as reported by the mother. The cause of the disability was a delivery fault as the doctors told them. Therefore, no one is guilty or had a mistake in this situation. However, when the last child came to the world as a multi-disabled individual, questions were directed to the mother by the father. Then, the father started to ask many questions although he knew their answers, to the mother and blamed her. The mother said that:

> The acceptance became very difficult for my husband. My husband wanted to discuss about it frequently. I mean he always looked for the reason. Since

> he had some difficulties in acceptance, he tried to find an answer. He was directing the questions to me. He believed something happened to the children during the pregnancy time because of me. I took medicine in both of my pregnancies. But I didn't take any with Ayşe. Of course all these accusations happened after the third baby. Not after the first one.

The reactions of the father might be considered as normal. If these reactions continued like that later in life, it would have then resulted in some problems. The particular support of the father admitted by the mother was his acceptance of the undesirable situation and stopping thinking that the mother was the guilty one. The mother said that "If he had carried on like that, my marriage would have been a disaster and it would be unbearable for me." The change of his reaction and later his support gave courage to the mother. She stated that "…he started to make jokes, care about me and the children more. I would take the children to their school, and when I came home; I would see that he had prepared tea for me. Such behavior made me strong, as well."

Apart from the father's emotional support for the mother, his participation in the caregiving process was insufficient. He supplied the financial needs of the family and he did not deal with the caregiving process of the disabled children like feeding, dressing, toileting, and bathing them.

The mother in my study does not complain about this lack of care taking roles of the father. Due to coming from eastern Anatolian cultural background, she obeys the social norms and was able to be happy with other thing which is closely related with her personality. According to her what he does is enough and he carries out his duty.

4.4. Extended Family Impact on the Mother

As we all know Turkey contains various kinds of cultures and regions. The culture of the east is one of them. This culture appears to be much more traditional than others. In terms of the family structure, it imposes an extending role on the mother. Also, expectations of this culture from the mother are much and it includes mother care roles, house keeping roles and marital roles. The mother in my study belongs to such a cultural background. From a perspective, eastern culture makes the living condition with disabilities better in that they show more depended feature towards each other. The family members are more connected with each other. In this case they show closer relation with the disabled family members, as well. However, from another perspective it brings some difficulties in terms of mothering roles. Furthermore, another expectation of the eastern culture is for a mother to deliver a male baby which allows the husband's surname to be carried on for years after he dies.

In my study, although the family of the husband is from the east, their expectations towards the mother regarding of roles were not very strict. According to the mother, the family of the husband did not ask her to deliver a male baby. She stated:

> Although my husband's father is from the east, he said to me that they didn't want a boy; they just wanted me to deliver another baby. He said our two daughters were enough. This was what he told me.

Apart from this when I asked her "Did they put any blame on you?" she responded "No. I didn't experience any such blame. Both my husband's family and mine weren't like that towards me at all." Furthermore, questions were asked about the support of the extended family for the mother in rearing the disabled children. The mother answered as follows:

> Their acceptance and not blaming me for the disability was the support they gave me. My mother-in-law always says to me that my three daughters are more valuable for them than a hundred boys. Although my daughter could not hold their heads up straight and could not walk properly, they loved them so much.

Having to obey the rules of mother-in-law and father-in-law put the mother in difficult situations regarding her communication with them. The extended family tried to help the mother; however, they ignored decisions or ideas of the mother. The mother could not argue with the extended family member as if she did so she would be labeled as disrespectful as can be understood from the mother's comment below:

> When Sevgi was three years old, we went to my mother-in-law's home for a visit. They live in Diyarbakır. At that time, Ayşe was a baby. They offered that I leave Sevgi with them in order to help me. Although I didn't want to do this at all, I had to leave her with them. If I didn't do that, they might misunderstand me as if I didn't believe that they can look after her. Then for two months Sevgi stayed with them.

The impact of the extended family on the mother's child rearing roles sometimes is visible and sometimes invisible. It is certain that they have an effect on her caregiving decisions. In addition, any kind of interventions from the extended family and this intervention became a part of a normal daily life without aware of the mother.

4.5. The Relationship between the Mother and Disabled Children

There is a very strong and sensitive relationship between the mother and her disabled children. In order to understand this sensitive relationship I asked the mother to provide me with in-depth information about this interaction.

In light of discussion related to this issue several topics emerged including role of impairment, personality of the disabled children and love towards mother.

Hearing impairment was one of the important factors which limited the communication between mother and the children. Especially due to the late diagnosis the quality of the communication decreased much. Fatma stated the following:

> I asked her to do what I said, but insistingly she didn't do it. As a result, I insisted more. Then, we began to conflict and argue. However, this was because they couldn't hear me, but I didn't know that then.

Another issue which has an effect on the communication is the personal characteristics of the children. Although the children were diagnosed with the same disabilities, their personalities were completely different from each other. As the mother stated:

> Sevgi is a confident person. She tried hard to participate in tasks. She trusts in herself. But Melek is more dependent on me. Unlike Sevgi, she is an easy going child. I think Sevgi can do, can stand on her feet but Melek needs me. Although the school is very close to our home, I take her everyday. But Sevgi never wanted me to take her to school.

Another aspect within the communication process between the mother and the disabled children is their strong loyalty and love towards their mother. They are aware that most of their primary needs are provided by their mother. Fatma said:

> One day my mother-in-law asked them: "Who do you love more, your mother or father? They immediately singed me with their fingers. Then my mother-in-law said: "You are right." I maintain all their needs. The person who asks them if they are hungry or not is me, who deals with their toileting is me. They are aware of that.

The children show their love towards their mother with some behaviors as mother said "When they saw that I was ill, Sevgi brings medicine for me; Melek comes and points to the place where I hurt. They become very worried. They even cry."

The communication between the mother and disabled children is so strong because there is love and care among them. Also, they are aware that they need each other and love each other. Moreover, they believe that their friendship gives meaning to their life.

4.6. Siblings' Relations

There was a relation between the healthy sibling and disabled ones. This mutual relation was sometimes positive and constructive; however, it sometimes creates conflicts and discussions. The mother unpreventably gave most attention to her disabled children and she ignored her healthy child's needs:

"Having dealt with my disabled children, I sometimes forgot, Ayşe. And I didn't recognize this until I heart her complaints."

This lack of interest caused the healthy sibling to develop jealousy and anger towards her disabled siblings. Moreover, the mother loaded responsibilities on the healthy child more than the child could tolerate. The mother did this without considering that she was also a child and needed care and attention as much as the disabled siblings did: “I was continuously telling Ayşe to look after her sisters. I didn’t allow her to get angry with her sisters. I warned her.”

Apart from these negative aspects of sibling relation, there is a constructive relation between the siblings. The healthy sibling has a great affect on all of the developmental domains especially social development of her disabled siblings. This affect is especially vital during the period of childhood since they play together, share, and cooperate with each other. These strengthen the relationship among them. As the mother said “Ayşe provides important support for her sisters even more than me.”

4.7. Coping with Disabilities within the Society

Having experienced with disabilities and disabled children, the mother had to cope with many challenges. Initially, the mother had to adapt herself to the idea of living with disabilities and disabled children. She had to cope with the existing obstacles because of the disabilities, as well. The obstacles might include daily life experiences such as eating, sleeping, shopping, going outside, and visiting a neighbor. As the mother stated:

> It was very difficult for me to go out with them. Because they can’t walk as we walk. I had to use a wheelchair for Melek. Their unusual walking attracts attention of people. It was really disruptive. But we got used to that and I don’t care about it as much anymore.

The mother had to cope with not only the people’s unusual and strange looks but also their compassions. She said “I don’t want people to look at my daughters and say ‘poor girls’ so I didn’t let them to do that.”

It was understood from the mother’s statements that the society underestimates the disabilities and disabled children. This causes both the mother and the disabled children to feel embarrassed. The disability itself is not a concept for the society to accept that easily. It is concept that initially society denies as mother did so herself. It is a very difficult task to live with handicaps for a disabled child. The disabled children cannot walk, hear, eat, use toilet, study, and speak as other normal individual. Being mentally and physically different from other people, both disabled children and the mother faced with the denial of the society. The mother had to cope with society and struggle to persuade people to accept her disabled children.

The mother had to cope with the feeling of immense sadness, as well. Because of the motor abnormalities her children fell down frequently, especially the youngest one. It was not possible for the mother to go out and visit with the children. The disabilities limited her social life. This might cause damage in her psychological well-being. However, the mother with time could become stronger about this case. After adapting to the disabilities and living with her disabled children, she was able to tolerate and got used to the situation much better. She stated:

> Whenever Sevgi fell down on her knees, she got bruises. I got the same bruises in my heart, too. From falling down so much their knees became calloused and thicker. Also my heart became calloused and thicker. But, I don’t become sad like I used to.

The mother also copes with living with more than one disability in her children. Both the mother and the children experienced difficulties especially during school. The mother said:

> Although Melek's friends had hearing impairments, it was sad that her friends didn't let her play with them. Since Melek has more than one disability, her friends didn't accept her. She can't run and play as they do so they didn't want to play with her and include her in their peer group. This upset both me and her. It took some time for them to accept her as a peer.

The mother provided answers to the questions of people patiently and provided lengthy explanations to them for some time. Later in time, people understood her and accepted the disabled children as they were. Such a consequence occurred because the mother behaved brave enough and could tolerate people's strange behaviors and sayings about her disabled children. Just like the mother, the society was able to adapt to the disabled children and live with them in the same environment.

4.8. Quality of Support of Services

The result of the interview demonstrated that the mother found the support of services insufficient. The most important deficiency occurred in the hospital; the doctors recognized the disabilities too late. This unfortunate event affected the disabled children and the family throughout their whole lives. It is very well known that the earlier the diagnoses the better the intervention for the children. By means of earlier diagnosis, the disabled children would have demonstrated a faster process in their development. As the mother said "It was a very big mistake of the doctors. If they had recognized the disabilities earlier, my children wouldn't have become like that and maybe every thing would be different."

Except for these negative outcomes, the mother took support for how to behave and communicate both with her healthy child and disabled children from the counseling teacher and special education institutions. The information given by them especially about the sibling relation satisfied her in some way. She said:

> By receiving training, I understood that I should have behaved to my disabled children like normal children, and shouldn't ask for much help with my disabled children from my healthy child.

However, the government schools didn't satisfy the disabled children' primary needs in terms of educational support since there have been very crowded classrooms that contain forty, fifty or even sixty students. In such crowded classrooms it is not possible for the teacher do deal with each child and especially the disabled ones individually. The mother indicated that "Sevgi was going to the school with forty students. Therefore, she couldn't learn anything from the school. Also she couldn't take anything from the teacher."

The support of the government was also insufficient for the mother. It was stated by the mother that the government does not provide enough support and is not sensitive enough to the physical and emotional needs of her disabled children. She complained about the lack of counseling services provided for them:

> The government provides financial support to the family of disabled children. They ruled that in a family in which the salary of the father for per member is less than 288 YTL, no financial support would be provided. However, since in each member of our family receives 300 YTL, we cannot take advantage of this support. Moreover, I have two disabled children, not one.

In general the mother received support from the special education institutions and she considered this help as useful. However, she expressed that she needed more educational, social and individual support for herself and her family. She expressed that the education should not only be given to the parents of disabled children but also to the teachers of their disabled children at school, and other people in society.

4.9. Mother Anxiety about the Future

Throughout the interview with the mother another important theme, anxiety of the mother about future, emerged. The mother was mostly worried about the future because she was worried about what would happen to her disabled children and look after them after she died. She said: “I pray to God to take our souls at the same time. I am worried about what will happen to them after I die.”

This anxiety does not only affect the mother. The healthy child shares the same feelings with her mother, as well. Moreover, Ayşe proposed some solutions to her mother. The mother stated as follows: “I told Ayşe not to think about the future. She said to me that she would work, earn money and look after both me and her sisters. And she tries to calm me although I don’t speak about this subject at all. I think she feels my worry.”

In order to overcome the anxiety and worry she experiences about future, she used several strategies. Firstly she observed other people share the same worries. She stated as follows:

> I realized even the mother with healthy children have worries about the future. They worry about their children’s future after they die or they worry about whether their children will take care of them or not in their old-age. I think all the people have similar worries like me.

The experience and the feelings of the people around the mother have given courage to her in that she feels she is not the only person who has worries about the future. Also she said:

> One day my mother in law said that 'you have two disabled children and you cannot look after me". I responded to her 'Look you have two sons and both of them are healthy. Think about me I don't have any son and two of my children are disabled. Who will take care of me? I told her that we must be patient and trust God. Although I am in worse situation than her, I was stronger. Then, I realized that this is not only my worry. An old woman, a mother or a father may have such a fear.

Another important concept which makes her feel comfortable is again belief in God. She believes that God prepares a future for herself and her disabled children. She believes that there is no need to worry about the future from now on.

In light of the mother's anxiety related to the future, I realized that the mother trust God much more than anything. Since she said "Thank God I am healthy, God gives me power and health to take care of my children. I believe that he also takes care of them." I observed that she directed the solutions of her future anxieties to the spiritual beliefs. These beliefs and feelings make her feel more comfortable.

CHAPTER V

DISCUSSION AND IMPLICATIONS

The aim of this mother-focused case is to contribute to the literature by establishing a profound understanding of the experience of the mother with multi-disabled children. Several themes came out as a result of my interview conducted with the mother. In this chapter, I discuss the results of this study with support of the related research and literature, explain the implication of the theory, report the limitations of the study, and finally state implications for the future research.

5.1. Discussion

In this part, several subjects are discussed in the light of family systems theory in light of the results of my study. These subjects include the multi-disabled child within the family, Family Systems Theory and the disabled children, spiritual belief and religion in relation to the coping of the mother, diagnoses and early intervention, and quality of services for disabled children in Turkey. These topics were discussed with focusing on the mother.

5.1.1. Family Systems Theory and the Disabled Children

A general systems perspective examines how components of a system interact with one another to form a whole. (Culatta & Tompkins, 1999). The family systems theory focuses on family behavior rather than individual behavior. The theory considers communication and interaction patterns, separateness and connectedness, loyalty and independence, and adaptation to stress in the context of the whole as opposed to the individual in isolation. (Chibucos Leite & Weis, 2005).

The results of my study revealed that there was a degree of dependence among the family members indicated as “interdependent components” (Freedheim, 2002, p. 279) in family systems theory. Family members including the multi-disabled children are mutually influenced by each other. Furthermore, they are mutually dependent upon one another. The mother depended on mostly the emotional support of the other family members including the father, healthy sibling and extended family. She mainly focused on the degree of that emotional support. The results indicated that the mother was dissatisfied about the insufficient emotional support of the father following the birth of last multi-disabled child. It was found that the father blamed the mother as not being the careful during the pregnancy period and he brought up the topic of the painkillers that she had taken during her pregnancy. The mother had to stand up to accusations of the father. During this, the mother had to cope with the lack of sentimental support of the father. The results showed that while the father demonstrated a more problem focused attitude, the mother took on the roles of balancer and manger. The finding of my study was supported by MacDonald, Fitzsimons, and Walsh (2007). They examined the use and coping strategies among family of children with intellectual disabilities. The researchers found out that female carers tended to use more "problem solving" strategies than males. Additionally it was revealed that male carers tended to use more "managing meaning" coping strategies than females. Besides this, both males and females careers shared some strategies. It was stated by the researchers that supporting not only the female but also the male carers was significant in order to reach high standards of care for the disabled children. The mother faced many challenges and difficulties in rearing her disabled children. She had to cope with many obstacles both internally (within the family) and externally (people around the family and school). Mothering disabled children and coping with the disabilities was a hard task for the mother, as severely disabled children of all ages are highly dependent on their parents to meet their basic care and treatment needs. In fact, older aged disabled children might have social, communication and behavioral problems (Herbert, 2005).

The results showed that the mother needed the healthy sibling to help and share of responsibilities of the disabled children in order to supply the self-caring needs of the disabled children and support their educational needs. The mother stated that the healthy child also had some needs. Similar to the disabled siblings, the healthy child demanded the interest and care of the mother.

Also, the mother stated her need for extended family support, too. Her adaptability deepened on the emotional support of the extended family. The mother stated that the extended family supported her emotionally in some degree. They accepted the disability and disabled children and encouraged mother emotionally.

The results demonstrated that the mother lived with disability and disabled children in terms of this support and share. This share and support made the family member hold on to each other and help the mother to be strong against this unpleasant situation.

The findings of my study also indicated that the relationship between the mother and her disabled children was essential in helping the children to adapt to social life. As a result, the disabled children developed confidence and trust in themselves. This increased the performance of the disabled children while working on tasks within daily life. This strong relation had positive affect on the mother, as well. By the means of strong attachment between the mother and the disabled children, she could hold onto life and could stand through the difficulties and overcome them much better. Similar to these results of mine, Lessenberry and Rehfeldt's (2004) study indicated that the interactions of parents with their children with disabilities could have a profound impact on the child performance in therapeutic or educational programs.

In the family system there are "boundaries". They are related to limits, togetherness, and separateness (Perosa, 1980 as cited in Winick, 1996) within the family and boundaries were close and limiting. This means that the family emphasizes togetherness, belonging, emotional connectedness, and sometimes agreement (Winick, 1996). The results of the current study also indicated that the concept of the disability made the family members connected to each other more and be affected from the external factors less. For example, the mother was exposed to be unusual looking and questions of the people around the family. She created a boundary that limits the innervations and compassions of the environment. This study also uncovered that the mother had to cope with not only the care of her disabled children but also the reaction of the society. It was found in the current study that society initially had a disturbing affect on the disabled children at first.
Society was perceived to be judgmental. The acceptance and adaptation of the society to the disability and disabled children took some period of time. Similarly, it was reported that disabled people are fighting for a society which does not consider

the differences and react to physical, sensory or intellectual impairments, or emotional distress, with fear and prejudice. It was suggested that society should recognize the difficulties that disabled individuals face but also value them as they are human beings (Zinkin, McConachie & Scherzer, 1995).

The results of the study revealed that there were boundaries between the subsystems such as marital and sibling subsystem. These boundaries among the subsystems include the marital subsystem, sibling subsystem, and the extended family system. The relation between the father and the mother has a degree of limitations and clear boundaries of responsibilities. The mother obeys the boundaries. The sibling obeys the rules and the boundary created by the mother, father and the extended family. Moreover, there is a degree of respect among the sibling and the other family members. The disabled children, on the other hand, have a special place and importance within these boundaries. The disabled children determine the boundaries. This is because the disabled children need continuous support and aid which have to be supported not only by the mother but also the father, healthy sibling and extended family. This important situation softens the boundaries among the subsystems. For example the father does not expect the mother to clean the home or prepare food every day; the healthy sibling does not wait from the mother to focus on her in her daily life experience, and the extended family do not expect the mother to look after them in their old age.

As it was mentioned in the family systems theory, there is hierarchy of subsystems within the family (Chibucos, Leite & Weis, 2005). This hierarchy depends on the gender and age and is influenced by culture, religion, or/and economic status (Silverstein & Ruiz, 2006). The results of my study pointed out that there is determinative role of the extended family. The mother emphasized the importance of taking their comments in applying the tasks related to the disabled children as taking them to the hospitals outside the city they live in, encouraging the family to search for educational support and to move to another city for this purpose.

Families may have some difficulties when the members or tasks related with each subsystem become blurred with those of other subsystems. For instance, when a child becomes involved in the issues of the marital subsystem, difficulties often emerge that require intervention. Especially if the child is disabled this may cause the parent to have more challenges (Knoblock, 1987). The results of my study demonstrated that the birth of the disabled children had an effect on the stress of the mother and the father in that they did not know how to deal with the babies and how to satisfy their primary needs, how to behave towards them, how to educate them and how to get used to living with them. The experience of stress and other challenging situations as mentioned is supported by a number of studies. Trute, Hiebert-Murphy and Levine (2007), Murphy, Christian, Caplin and Young (2007) and Duygun and Sezgin (2003) pointed out that families with disabled children also experience significantly higher stress levels than families with non-disabled children. In fact, the child’s disability itself may contribute to parental stress. The care giving requirements such as feeding difficulties and behavioral disturbances can raise parental stress especially mother stress. The care giving needs of the disabled child is mostly met by the mother. This increases the stress of the mother compared to the other family members. In addition to this, lack of communication skills of the disabled child and his/her difficulty in mastering developmental tasks can also lead to increased levels of stress in parents. Children with delays in more than one area or with more than one disability can intensify parental stress.

Another important component in the family systems theory was 'rules'. They could be both spoken and unspoken (Chibucos, Leite & Weis, 2005). The results of my study showed that the rules within the family were constructed according to the disabled children. Within the construction period of the rules the mother had a central role. The person who understood and answered the needs of the disabled children was the mother. This reality gave her a chance to change or reconstruct the rules. For example, she decided on the daily life experience of the children and permissions are taken from the mother. The father usually controls the mother about activities that will affect the whole family such as traveling outside the city or changing his occupation. All household rules have been adapted to the disabled children's needs.

The emerging of the 'goals' come out as a result of the rules and boundaries of the family system (Chibucos, Leite & Weis, 2005). The results of my study showed that the whole the family shares the same goal which was to provide a good living condition for the disabled members and the person who share this goal and who worked to reach this goal physically and emotionally was the mother. This goal brings anxiety about the future of the disabled children. All family members share this worry to a degree; however, the mother experienced this anxiety and worry more than the other family members.

The results of my study showed that the 'feedback mechanisms' (Chibucos, Leite & Weis, 2005, p. 280) were mostly positive. The mother took the positive feedback of the other family members. Nevertheless when diagnoses of the disabled children were new the mother was exposed to negative feedback related to the deliveries the disabled children. The mother stated that before the birth of the last child who had multi disabilities the father-in-law warned the mother not to deliver another baby and he emphasized that they did not expect a male baby from her. The mother stated that with time their negative feedbacks changed into positive ones.

When the mother and her family were examined with the concept of 'change' (Chibucos, Leite & Weis, 2005, p. 280), which is defined as adaptation to new patterns, it was revealed that both the mother and her family had an adaptation period to the disabilities. The disability and the disabled children were a new pattern that family faced with. The adaptation period took a long period of time for the mother and the other family members. The results of my study indicate that this new situation changed the structure and function of the family to a certain degree. The structure and the relation among the family members were stricter and more formal, however, with the arrival of the disabled children it became softer and formality reduced.

Furthermore, the results of my study were consistent with previous studies in that the of the disabled children had changed the condition of the healthy child in that the mother unconsciously expected her to look after or take care of her disabled siblings. Findings of the study of Macks and Reeve (2007) also indicated that having a disabled child can also greatly affect the well-being of non-disabled siblings in the family. Parents need to make an effort to psychological well-being of the other children in the family. Also, non-disabled siblings may experience lack of parental attention and an increase in their daily responsibility. Besides this, they are in a risk for poor relations, lower participation rates in relaxing activity activities, and loss of friendship.

The results of my study also revealed that the father and extended family had affects on the mother in terms of well-being, rearing the disabled children and coping power. The father affects both the mother and the family dynamic as a whole. He supports the mother emotionally and financially. The emotional support has the greater affect on the mother more than his financial support. The initial need of mother was sensual support of the father. It was reported in this study that emotional support of the father increased and had a positive affect on the mother's well-being. As a result of that, the mother coped with arising troubles much more efficiently. Additionally, it was noted that the mother used more care taking roles of the disabled children. When the mother's and father's responsibilities related to the rearing of the disabled children were compared, it could be seen that most of the responsibilities are shouldered by the mother.

5.1.2. Spiritual Belief and the Religion

In addition to the support of the father and the extended family, spiritual belief and religion played an important role in the mother's acceptance of the multi-disabilities. The mother calmed herself and tried to balance her psychology during disruptive consequences of the disability and its difficulties in daily life. While applying this behavior, she mostly trusted and depended on religion. As a result of her belief, she could have a healthy perspective and living condition.

Similar to my study, in a study conducted by Hughes (1999), researcher examined the coping mechanisms of 34 parents of children with disabilities and the researcher found that families who were active in church appeared more able to cope with stress and maintain a positive perspective for their child. However, Akkök (1996) found that children with mental retardation and autism to determine the disabled child's effect on the relationship between stress and causal attributions. She identified four causal attributions: personal characteristics and conflicts with the family, spouse and others (external blame), external specific situations like work and environmentally related problems (specific external condition), and attributions to fate and bad luck. It was revealed that the level of stress in the parent-child relationship was significantly related to causal attribution. Mothers with higher stress were found to make attributions to bad luck. However, the results of my study did not identify such a finding. The mother did not recognize and handle the situation as "bad luck". Rather she approached the circumstance as "fate" and managed it with support of her family and faith in God.

5.1.3. Diagnoses and Early Intervention

In the diagnoses and early intervention period not only the mother but also the father had an important role. Since in this period the mother in my study emphasized the help of the father in that he is the one who took the disabled children to the hospital in another city and dialed with their health needs closely with the mother. The results of my study were similar to the findings of research by

Hadadian (1994). He pointed out that in delivery of early intervention services active engagement of fathers is essential.

Another aspect of my study was that: there were inadequate intervention and services in both diagnosis periods of the children' disabilities and the education of the children. It was acknowledged that early intervention is essential in that it could be very effective in improving childhood health and development (Feldman, 2004).

It was proven that effective treatment depends on reliable diagnoses. The physician stated clearly that a diagnosis would give reliable descriptive criteria including what is the problem, the source of the problem and how to help the family. Furthermore, early detection of disorders is crucial for both children and their families. Certainly, diagnosis of the disability of a child at an early age has important effects on the future development of the physical, intellectual, emotional and social development of the child. Therefore, interventions can be planned to enable them to develop their independence and the potential to participate in everyday life (Herbert, 2005).

The importance of the early intervention and diagnosis also emerged in my study. Because of the doctors' late diagnosis and intervention, the disabled children became more vulnerable towards outside effects. They could not benefit from and attend special education and rehabilitation service at the appropriate time which was the early period of childhood. As a result of this late intervention the parents had stressful times and to reduce this stress both the mother and the father used some coping strategies. These coping strategies were firstly taking emotional power and support from each other and other family members. Secondly, they received information from the doctors and special education institutions. This finding of my study is consistent with a study carried out by Graungaard and Skov (2007). It was reported that parents of disabled children engaged in a wide range of different coping strategies to reduce the stressful feelings, and the use of different coping strategies was influenced by the certainty of the diagnosis.

Additionally, my results indicated that during the diagnostic period the mother and other family members lived stressful times. They had to develop some coping strategies in front of such an unexpected event. For instance, the family used more problem solving skills; the family members tried to help the mother to some degree. The result of my study was supported by Stone (2000). The researcher examined the coping strategies of parents with multi-disabled children. The researcher found that in order to cope with the multi-disability and their multi-disabled children parents used a high level of problem solving skills, looked for social support, and showed a low level of avoidance.

Also, Kelso, French and Fernandez (2005) conducted a qualitative research .The result of the study revealed common stresses faced by caregivers such as the families experienced confusion about where and how to find help for their disabled children. Also, the results demonstrated that caregivers search for coping resources and used strategies in order to deal with their children’s disability. Another finding of the study was that most of the participants adapted well to the requirements of raising a child with a disability. The results of my study also demonstrated that the mother by taking the family members support and receiving assistance from the special education institution adapted with the condition of living disabilities.

5.1.4. Quality of Services in Turkey

My study found out that the mother was not satisfied with the opportunities of the special education and she complains about the insufficient care of the Turkish government. In Turkey, the government brought out a new circular letter which was about the disabled children and the educational support provided for them. For many years, the government attempted to prepare a base for special education and disabled children. Initially, the government provided some facilities such as providing care for disabled children within their homes and free counseling for these children. In our country all the institutions that provide education and rehabilitation for the disabled children were connected to the ministry of education. With this change, all families whether they had social insurance or not, could benefit from the special education. This has brought valuable contributions to the field of special education. The education, especially the special education for children with special needs should be in the control of the government.

The circular letter is a paper which was published by the government about the disabled children and the special education institutions. It started to be applied on the November 2007 with the aim to protect the rights of disabled children in a way that most of the children with special needs must attend only the governmental schools. From another aspect the circular letter may prevent the children who attend state special education schools and the same time attend another special education institution. If government decides to close these special education institutions, then they will have to assign or hire more personnel to educate disabled children and allocate a higher budget for these disabled children (Retrieved from www.meb.gov.tr, 2008).

Another change which this current circular letter brought was that children with special needs who had studied in an integrated class which means taking education in the same classes with their normal developed peers could only take individualized education not group education. This change aimed to combine both the school curriculum and the rehabilitation service. The government tried to prevent the private sector in profiting from disabled people by centralizing and publicizing the education and rehabilitation of disabled children by maintaining itself the appropriate education for children with special needs. Although this new effort tries to protect the rights of both the disabled children and their families, it applies this new change without a contractive preparation. Not preparing an appropriate background for this change, both the disabled children and their families face unfair treatment.

5.2. Limitation of the Study

This study includes several limitations. One of the limitations might have been participant and interviewer bias which occurred in the process of the interview. The interviewer might have influenced the participant from an opinion in that the interviewer might focus on specific information rather than letting the participant be as free as possible. The participant may not feel comfortable and relax while sharing her most personal and special concerns, feelings or challenges in the face to face interview. Moreover, the participant may have been provided socially desirable responses to please the interviewer (Fraenkel & Wallen, 2003).

Another limitation was that the result cannot be generalized to a larger population. Some of the biases could occur in the selection of the participant in that the characteristic of the mother may have an effect of the researcher (e.g., easy, nice, or cooperative mother).

One bias that can be seen in this study is that the sample is not random since the participant was chosen due to the availability of the subjects. Some misunderstandings may also have occurred if the interviewer asked questions that the mother may not have understood. The last limitation was the use of limited data collection instrument; only interviews.

5.3. Implications for Theory

The family systems theory provided the theoretical framework for my study. In the light of this theory, the experience of the mother with her multi-disabled children, her coping strategies and stress due to her disabled children were examined. By the means of this theory, the interrelations among family members regarding the disabilities were investigated. This theory emphasizes the examining of the disabled children from a systems perspective in order to discover individual members' interactions such as mother, father, and sibling effects related to stress and coping (Sivberg, 2002).

Another contribution of this theory is that it brought insight about understanding problematic issues within the family and communication patterns.

The concept "psychological well-being" of the disabled children was also another finding of this study. Disabled children were also aware that they were different from others and living abnormally which brings some psychosocial problems within the family and the society. Johanna (2003) conducted a study on the personal experiences of the learning-disabled child within the family. He indicated that children with learning disabilities often experience psychosocial problems. These problems not only had an influence on the parent-child relationship, but also impact negatively the psychological development of the child. The researchers primarily employed projection techniques to investigate the child's experiences of himself and his relationships with family members (Johanna, 2003).

The results of my study indicated that the family dynamics and relation among the family members become more sensitive because of the presence of the disabled individuals within the family. In this dynamic, the mother is the member who was affected the most due to this sensitive situation. It was also noted that there is an acceptance process not only for the mother but also for the father, sibling, extended family and the society. This extended interaction could be examined deeply with other theoretical models as ecological theory of Bertalanffy (Russell, 2003). Such a study would contribute to my study.

Previous research mainly focused on the difficulties of being parents of children with disabilities or negative aspects of having disabled children. (Saloviita, Italinna, & Leinonen, 2003; Plant & Sanders, 2007; Murphy, Christian, Caplin & Young, 2007; Hastings, 2005; Eccleston, et al. 2004; Hung, J Wu, & Yeh, 2004; Hassall, Rose & McDonald, 2005). However, my study on the structure of the family systems theory contributes some positive aspects of rearing a disabled child. Some of the comments reported by the mother included: “Not only I experienced sadness with my disabled children but I was also happy to be with them. I learned many things from them. I become stronger and I did not give importance to daily stressors as much. I didn't discuss small details with the people around me. I matured quickly." Therefore, this positive aspect of rearing disabled children within the family systems perspective needs to be explored deeper.

Earlier research has supported the idea that spiritual beliefs and religion are factors that help the mother recover from difficulties and experiences of stress because of her disabled child (Hughes, 1999). The mother in this study also reported that her spiritual beliefs and practices were very important in dealing with life circumstances in regard of disabilities. Hence, this protective factor associated with the mother of disabled children should be examined profoundly within the family systems theory.

5.4. Implications for Professional Practice

From the results of my study, several implications for professional practice clearly emerge. It is crucial that special education and rehabilitation centers, family therapists, counselors, and school personnel understand the complex process of stress and its impact not only on mothers, but also on the family as a whole.

Firstly, my study emphasized the importance of early intervention. It is crucial to examine disabilities and informing the family and other people associated with the disabled children such as counselors, and school personnel about their children' disability so that early intervention can be provided. It was reported that impact of early intervention on both child and family were significantly related to each other (Bailey, Nelson, Hebbeler, Spiker, 2007). Bailey et. al (2005) states that early intervention provides important supports for families of young children with disabilities. Additionally, early identification and efficient directions are important so that maximum benefit can be realized for children with disabilities and their families.

Secondly, in the practical field after diagnoses of the disabled children parents are in intense need of supporting services. Bailey et. al (2005) examined family outcomes at the end of early intervention near the child's third birthday. The results of the study revealed that at the end of early intervention, most parents felt competent in caring for their children, obtaining support from services, and gaining access to formal and informal supports. The findings stated that the families were generally optimistic about the future and most of the parents believed that their family was better off as a result of early intervention. On the other side, parents were quite less positive in their perceived ability to deal with their child's behavior problems or gain access to community resources. It was indicated that the role of high-quality services in maximizing perceived impact on young children with disabilities and their families. The informal support in promoting optimism and confidence in parenting with young children with disabilities is important. If the child is poor, a minority and of poor health, it was concluded that the quality and benefit of services were lower.

Moreover, the quality of family services was related to both child and family impact. Also, informal support was not related to perceived impact on children or families, but was strongly related to confidence in parenting and optimism. The results indicated that minority families and families of children with poor health reported lower quality of services. However, these characteristics did not reduce the intensity of the relationships between services and perceived impact on the child. On the other hand, both poverty status and minority status were related with perceptions of impact on the family (Bailey, Nelson, Hebbeler & Spiker, 2007)

Thirdly, social support should not only be provided for the parents' but it should also serve the healthy sibling. Rivers and Stoneman (2003) pointed out that parents had less interest about sibling communication and interaction. In addition to this, healthy sibling indicated satisfaction with her or his disabled sister or brother. It was found that families experiencing high marital stress looked for support from formal resources outside its family environment. The results of the study emphasized the significant role of the family context on quality of the sibling relationship. The parents appeared to be the balancer and facilitator between the healthy and disabled children relation (Rivers& Stoneman, 2003).

Fourthly, it is important to provide therapy intervention for the mothers of disabled children. Helitzer, Cunningham-Sabo, VanLeit, and Crowe (2002) conducted a study on changes in the perceived self-images and coping strategies of mothers of children with special needs after they participated in a short-term occupational therapy intervention. Researchers indicated that after intervention mothers could share their perceptions of their self-image such as feeling overwhelmed with their daily care routine, being socially isolated, losing their identity, and expecting less from their careers. Mothers of children with disabilities reported that participating in the program helped them to feel strong, attractive, resilient, respected, and accepted. Additionally, they stated that after participating in the program, they expressed they had gained coping skills such as increased ability to advocate for themselves, had more relaxed expectations about their responsibilities for their disabled child, had more information on what is needed to care well for their child, and increased self-care practices.

Finally, an implication for practice is seen in the further development of rehabilitation services in the life of the family. Rogers and Hogan (2003) conducted a study on the effects of children's medical impairments and functional disabilities and the use of medical care and rehabilitation on three family consequences including job changes, severe financial problems, and sleep disruptions. They found that rehabilitation services serve as a mediator between the children’s medical impairments and disabilities on these family outcomes.

5.5. Suggestions for Future Research

In light of this current study through the review of literature, it appears that future research should focus on mother and disabled child interaction. Especially the research conducted in Turkey mainly employs a quantitative research design. Therefore, there is a lack of attention given to qualitative researches. It would be useful for future research to use the qualitative design in order to understand and give insight about experiences, children rearing decisions, and stress and coping of families with disabled children. Furthermore, in order to have thorough knowledge about the relation between the mother and disabled child and mother’s coping and stress within the family system, longitudinal studies could bring profound information.

The results of this study suggested that the mother had coping skills, and experienced stress while rearing her disabled children. The results also revealed that not only the mother, but also the father and the sibling were influenced by the disabled members within the family. Therefore, it is important to continue to do in-depth research about how coping and stress impact factors influence other family members.

The result of this study indicated that there is a difference in respect to the care taking roles between father and mother. It would be useful for future studies to examine this difference in depth.

This study mentioned about some external factors. Future research needs to investigate these external factors that effect the mother-disabled children interaction such as extended family, school and the society as a whole.

Another recommendation would be to replicate this study using more than one participant. It would bring perspective about how mothers coping strategies are different or similar with each other or from which denomination their experiences show similarities or differences.

Additionally, the quality of service in Turkey could be studied by future researchers. This will bring knowledge about the number and nature of counseled participants, and whether rehabilitations services satisfy the needs of the family of disabled children. In this study, the results expressed the importance of early intervention regarding the early diagnosis of disabled children. Hence, future research could also focus on this issue and bring a broader perspective on quality of Turkish health centers.

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APPENDIX A

Interview Questions 1

1. What were your expectations and feelings before the first childbirth? What changed after that?
2. What were your expectations and feelings before the second childbirth? What changed after that?
3. In your opinion, what are some of the particularly stressful issues in parenting a child with special needs?
4. When did you find out that your child/children had special needs and how did you cope with this new information?
5. How do you parent your multi-disabled children?

Interview Questions 2

1. What are the major concerns or frustrations you and your child face as a result of multi-disability?
2. How did the multi-disability affect your family?
3. Tell me about your relationship with your multi-disabled children?
4. What resources do you presently use to help with your disabled child/children? (For example; home care assistance, support groups, therapy, counseling, etc.)
5. What is the difference between the first child and second child in terms of your feelings?

Interview Questions 3

1. How does it feel to mother multi-disabled children?
2. What was the society's reaction to the disability and to your disabled children? And how did you cope with that issue?
3. How was the reaction of the father towards you and the disabled children? How was the process of acceptance of the disabilities and disabled children?
4. How was the reaction of the healthy child towards the disabled sibling? How was her acceptance process?

Interview Questions 4

1. What was the quality of the relationship between the healthy child and disabled children?
2. How were the disabled children's relations with the healthy sibling and the father?
3. How was the reaction of the extended family towards you and the disabled children?
4. Could tell me about the attitude of them towards you?