LIFE EXPERIENCES OF MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITY

GÖKÇE PİROĞLU AKÇAKMAK

BOĞAZİÇİ UNIVERSITY

2014

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Thesis submitted to the

Institute for Graduate Studies in the Social Sciences

in partial fulfillment of the requirements for the degree of

Masters of Arts

In

Educational Sciences

By

Gökçe Piroğlu Akçakmak

Boğaziçi University

2014

Life Experiences of Mothers of Children with Intellectual Disability

The thesis of Gökçe Piroğlu Akçakmak

has been approved by:

Assist. Prof. Z. Hande Sart ________________________________

(Thesis advisor)

Assoc. Prof. Fatma Nevra Seggie ________________________________

Prof. Barış Korkmaz ________________________________

May 2014

Thesis Abstract

Gökçe Piroğlu Akçakmak, "Life Experiences of Mothers of Children with Intellectual Disability"

The purpose of this study is to examine the life experiences of mothers of children with intellectual disability. In order to better understand how the disability of their children affects the mothers and their families better, it aims to give voices to mothers' stories from the pregnancy period to present by examining from the aspects of their experiences before and after the diagnosis of their children, their knowledge and needs about the disability, their mothering role in daily life, relationship with their family and society and also positive aspects of the disability in their lives.

Nine mothers whose children have intellectual disability were individually interviewed for this research study by means of in-depth interviews. Additionally, they were given demographic forms before the interview took place. The children were between 7 to 15 years old. Children were all diagnosed with mild intellectual disability at least 5 years ago and they were in inclusive educational settings and also they were eligible to receive special educational services from rehabilitation centers in İstanbul. All mothers in this study were housewives and they were from low to middle socioeconomicalstatus and from primary to higher educational level. Data obtained from interviews were analyzed by using thematic method.

Findings showed that being the mother of a child with intellectual disability was not only challenging but also pleasant for these mothers. Although they stated that they were tired due to the combination of needs mothers should fulfill for their children and the whole family, they were also happy to have a child with special needs from whom they learned different ways of living. They also emphasized their needs of support and how they were worried about the future of their children with disability after they would decease. Moreover, mothers were complaining about the discrimination in social and educational settings toward children with disability and how this negative attitude affected their lives.

The analysis of the data also indicated that mothers of children with intellectual disability had various problems in family and social life. Emotional stress of having a child with disability, discrimination of the child due to his or her disability, daily requirements of a mother at home, neglecting of other siblings and social life had pressure on these mothers. Due to these reasons, they expressed that they had lots of stressors in their life.

Tez Özeti

Gökçe Piroğlu Akçakmak, “Zihinsel Engelli Çocuğa Sahip Annelerin Yaşam Deneyimleri”

Bu çalışmanın amacı, zihinsel engelli çocuğa sahip annelerin yaşam deneyimlerinin araştırılmasıdır. Zihinsel engelli bir çocuğa sahip olmanın anne ve aileyi nasıl etkilediğini daha iyi anlamak için yapılan bu çalışmada katılımcıların çocuğunun teşhisinden önceki ve sonraki deneyimleri, engellilik hakkındaki bilgi ve ihtiyaçları, günlük yaşamdaki annelik roller, aileleri ve toplumla olan ilişkileri ve engelli çocuğa sahip olmanın yaşamlarına katkıları anneler tarafından dile getirilmiştir.

Bu amaçla, hafif düzeyde zihinsel yetersizlik tanısı almış 9 çocuğun annesi ile yüz yüze görüşmeler yapılmıştır. Görüşmeden önce annelere demografik form doldurtulmuştur. Çalışmaya katılan annelerin çocuklarının yaşları 7 ile 15 arasındadır. Çalışmaya katılan tüm çocuklar en az 5 yıl once hafif zihinsel engelli tanısı alarak kaynaştırma yoluyla eğitim kapsamına alınmış ve rehabilitasyon merkezlerinden özel eğitim almaya devam etmişlerdir. Çalışmadaki tüm anneler ev hanımı olup orta ve düşük sosyoekonomik düzeyden gelmektedir. Annelerin eğitim seviyesi ilkokul ve lise aralığındadır. Görüşmelerden elde edilen bulgular tematik analiz yöntemiyle analiz edilmiştir.

Araştırma sonucunda zihinsel engelli çocuk annesi olmanın yalnızca zorlayıcı değil, aynı zamanda mutluluk veren bir duygu olduğu görülmüştür. Anneler, birçok defa çocuklarının ihtiyaçlarını karşılamak için çabalarken yorulduklarını ifade etmiş olsalar da engelli bir çocuğa sahip olmanın onlara çok şey öğrettiğini ve bundan büyük mutluluk duyduklarını vurgulamışlardır. Çalışmanın sonucunda annelerin çeşitli desteklere ihtiyaç duydukları ve kendilerinin ölümünden sonra çocuklarına ne olacağına dair yoğun bir kaygı yaşadıkları görülmüştür. Ayrıca, anneler sosyal hayatta ve okul ortamında çocuklarının ayrımcı ve olumsuz bir tutuma maruz kalmasından rahatsızlık duyduklarını belirtmişlerdir.

Yapılan analizler, zihinsel engelli çocuğa sahip annelerin aile ve sosyal hayatlarında çeşitli sorunlar yaşadıklarını göstermiştir. Zihinsel engelli çocuğa sahip olmanın duygusal yükü, çocuklarının engeli yüzünden çeşitli ortamlarda dışlanması, annenin günlük ev yaşamında yerine getirmesi gereken sorumluluklar ve bu sebeple diğer çocuklarını ve hayatını ihmal etmesi annenin üzerindeki baskıyı arttırmaktadır. Bu sebeple anneler hayatlarını zihinsel engelli çocuklarına adamışlardır.

ACKNOWLEDGEMENTS

Writing this thesis is a long, stressful and tiring process that I have lost my hope to complete this study many times. In these times, I saw many people supporting me to continue and do my best. I am very happy to thank these people who are the motivation in my life.

First, I would like to acknowledge my sincere gratitude to my thesis advisor Assist. Prof. Z. Hande Sart for her guidance, patience and caring throughout the whole process. I would not be able to complete this thesis without her expertise, knowledge and never-ending energy. She has patiently corrected my writing for many times and has given feedback to make my thesis better than I expected her to do. I am glad to study with her due to her caring and responsible personality beside her knowledge and experiences in "advocacy in disability issues". I specially express my gratitude to her because she is the one who raises awareness about the issue of "disability" and makes me think of what I could do for these people to support them.

Besides my advisor, I would like thank to members of my thesis committee, Assoc. Prof. Fatma Nevra Seggie and Prof. Barış Korkmaz for their valuable contributions to my thesis. I thank to Fatma Nevra Seggie for her making me acquainted with "qualitative research" and love it. I could not imagine conducting qualitative research study before this thesis. I really trusted her precious recommendations and feedbacks she provided me. Also, I thank to Prof. Barış Korkmaz, despite his being too busy, he allocated his time to be in my committee and provided insightful comments.

This university gave me two precious gifts, one of which is my lovely friend Derya and the other one is my husband Erman. Many thanks should go to Deryam for her helping me to see the big picture in analysis by eliminating the details I always get stuck in. She made me laugh at myself when I freak out. I should also express my gratitude to my lovely husband who helped me start this master program and morally encouraged me when I felt down and worried about not being able to finish my thesis. He is my stress reliever and tolerant of my sullen face when I could not continue writing.

Additionally, I would acknowledge showing my gratitude to the mothers who frankly shared their life stories and opened the doors of their worlds to me. Mothers who were in my support group were the reason of my choosing this research topic. I am glad to give voices to their problems and different lives with their special children. They taught me how to be an altruistic mother in difficult situations.

Last but not the least; I would like to thank my mother, father and brother for their continuous love, always believing me and supports in my decisions. My parents made me love having ambition to study from my childhood. I learned not to give up and do my best from my mother who is a real researcher at birth. My father and my brother encouraged me to continue my thesis by their asking the never-ending question of "when will this girl finish studying?" Without whom I could not have achieved this study. This thesis is dedicated to my loved ones who are always supporting…

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CHAPTER I

INTRODUCTION

Having an offspring which brings lots of regulation and changes to the lives of the parents is pleasing but also a challenging life experience (Köksal, 2011). Child rearing is a complex and effortful responsibility for all parents because when a couple decides to have a baby, they also decide to change their life style according to the new roles assigned as being a mother or father (Alpöge, 2012). Furthermore, their social roles will change and they get new responsibilities such as caring the child, financing the needs of the new comer, regulating the health condition of the baby. Their relationship with each other, relatives and friends will change because they adjust their lives to fulfill the needs of their offspring (Alpöge, 2012).

As mentioned, the life of a couple who expects a baby starts to change before the birth of the new comer. During pregnancy, prospective parents experience some difficulties. For example, in the transitionary period to motherhood, the mother has to adapt to some physical, social, emotional and financial changes (Hoffenaar, Balen, & Hermanns, 2010). While the mother experiences these difficulties, her husband has also difficulties in adaptation to new situations. For example, he may feel anxious and sometimes may feel alienated because his wife, relatives and friends are not spending enough time with him (Alpöge, 2012).

In the first 3 months, the mother cannot believe the reality about her pregnancy and experiences extreme mood swings due to hormonal changes in her body (Murkoff & Mazel, 2008). Even when the pregnancy is planned, the mother has conflicting feelings about having a baby because she starts thinking of how her life will change after being a mother (Alpöge, 2012). Although the mother feels happy about her baby, she feels so weepy at the same time because she is worried about changes the baby will bring into her life (Alpöge, 2012). During pregnancy, the couple may also think of the situations regarding employment condition such as time allocated for maternity leave or mother's quitting job after the birth. These situations may affect the financial resources of the family due to the needs of new baby.

After the third month, the mother accepts being a mother and having a baby and has fewer mood swings but after this time she starts dealing with anxiety about the future (Murkoff & Mazel, 2008). The prospective mother imagines her expected baby by considering her own relationship with her mother, wishes, fears and expectancies (Alpöge, 2012). Her image of the baby in her mind determines her relationship with the baby (Alpöge, 2012). She wonders about the sex, personality, physical appearance and other attributes of baby (Seligman & Darling, 2007). Folk wisdom, interaction with relatives and friends shape the expectations of the parents from unborn babies (Seligman & Darling, 2007). For instance, baby's movement, mother's abdominal shape and size are seen as indicates of the unborn baby's sex, temperament or size (Seligman & Darling, 2007). With this information and hopes, the mother and father have expectations about their unborn baby and also their parenthood. They dream about how they take care about their baby, how the baby will play with them and even the future career and hobbies of the baby (Seligman & Darling, 2007).

Because pregnancy is a physically difficult period for the mother, she becomes worried about the health of the baby in the womb when she feels pain in her body (Murkoff & Mazel, 2008). Ideally, she pays extra attention to her daily diet, exercise and health to keep the baby healthy, too. Towards the end of the pregnancy period, the mother starts worrying about her mothering role and how she will look after her baby (Murkoff & Mazel, 2008). While the mother is dealing with her anxieties, the father considers about how he will finance his family and fulfill the responsibilities of baby (Alpöge, 2012). He is interested in whether the baby's development is normal or not. When the mother gets sick, the couple first asks whether there is a risk to the baby (Murkoff & Mazel, 2008). During pregnancy, the couples generally from middle to high socioeconomic status (SES) try to find medical doctors and hospitals where the delivery will take place (Alpöge, 2012). Pregnancy is a mutual process not only to focus on the needs of baby, but also expectations of parents.

But difficulties do not end when the child is born because mothers generally suffer from postpartum syndrome after the delivery and she has to adapt to her new role as a mother. Moreover, they are faced with new challenges such as sleep deprivation, learning caregiving tasks, and changes of life style (Harwood, McLean, & Durkin, 2007). After the delivery, the mother feels exhausted not only physically but also emotionally. In postpartum period, mothers experience pain, discomfort with regard to her delivery type (Murkoff & Mazel, 2008). She is frustrated, excited and also overwhelmed by the physical and emotional challenges she faces (Murkoff & Mazel, 2008).

This is the case of having a typically developing baby. But when a child with special needs comes to the family, it may create a crisis for all family members because they are not sure what to do, how to adjust their life to new comer with special needs and how to handle the emotional difficulties of this crisis. Since some of their expectations fall down, it becomes difficult for parents to cope with the new situation as well (Bayraklı & Kaner, 2012). When experiences of parents disconfirmed in a negative way, it is more likely that adjustment to parenthood is poorer (Harwood, McLean, & Durkin, 2007; Kalmuss, Davidson, & Cushman, 1992). After dreaming positive things about unborn baby, awareness of the disability of their child is difficult for parents to adjust.

Caring has a different meaning for parents of children with special needs because these parents have to meet the requirements of daily life while trying to cope with the chronic situation of their children (Azar & Badr, 2010). All members in the family are affected from having a member with disability but mothers of children with special needs are the most affected member of the family due to different reasons. First of all, mothers are seen as the primary caregiver of children and they have emotional bounding with their children (Rowbotham, Carroll, & Cuskelly, 2011). Secondly, they are spending more time with their children, so they feel more stress and responsibility to raise their children with special needs.

Therefore, the focus of this study is to describe life experiences of especially mothers of children with intellectual disability but in order to better understand the situation of children with intellectual disability, intellectual disability will be explained below in detail.

Significance of the Study

Depending on the existing research studies, it is well understood that examining the families of children with intellectual disability has been gaining importance because the disability in a family member has both positive and negative effects on the whole family structure. In this system, mothers who are generally primary caregivers of children with disability are affected from this struggle differently so that primary focus of the research studies has become mothers of children with disabilities.

In Turkey, when looking at the studies about mothers of children with disabilities, it is seen that studies are analyzing the dimension of stress, depression, hopelessness and coping of the mothers of children with disability in quantitative methods. Because of this reason, studies on mothers of children with disability do not go beyond indicating statistical data and studies do not fill the gap of understanding the experiences of mothers from the eyes of these specific group. Therefore, the main purpose of this research study is to examine the life experiences of mothers of children with mild intellectual disability in a more in depth way by the means of qualitative method.

Although limited in number, there are some qualitative research studies on mothers of children with disabilities in Turkey but they focus on some parts of the experiences such as daily stress, burn-out, types of coping, their views of disability etc. (Sen & Yurtsever, 2007; Diken, 2006). These studies highlighted the specific part of the life of these mothers and did not give the big picture. Thus, this study aims at understanding the life experiences of mothers of children with intellectual disability from both positive and negative dimensions of their lives.

Moreover, this research study was designed after 7-session-support group for mothers of children with disability. During the group sessions, mothers were educated in different parenting skills and expressed their daily life experiences with their children before and after the diagnosis of their children. After the group sessions, the needs of mothers of children with disability were assessed and by considering the needs of mothers and their lives, this study was conducted. Due to this reason, both mothers and researcher were educated with regard to lives of mothers of children with disability. Different from other studies, this study was combined by aiming to make the voices of mothers of children with intellectual disability heard. In Turkey, there was a study in which mothers joined a support group but that study examined the some variables about mothers in quantitative method. In order not to limit the study with some variables, our study examined the whole life of mothers of children with intellectual disability.

Finally, this research study will shed light on the lives of families of this special population from mothers' point of views. Therefore, data obtained from this study could help policy makers to make appropriate accommodations in order to increase the quality of services needed by this population.

Organization of the Study

Chapter II presents a review of literature on understanding the intellectual disability, common reactions of parents of children with intellectual disability and how to cope with the situation of having a child with intellectual disability with the findings of similar studies in Turkey and international arenas. Chapter III gives the information about the methodology which consists of research design, sample selection, data collection instrument and procedures used for data collection and lastly data analysis. Chapter IV provides the analysis of the data and the findings. Finally, last Chapter V presents summary and discussion of the findings, indicates the limitations of the research study and offers recommendations for further research studies.

CHAPTER II

LITERATURE REVIEW

The review of literature for the present study consists of three sections: In the first section, the definition, causes, prevalence, main features and diagnosis of intellectual disability are presented to have a better understanding of this disability. In the second section, common reactions of the parents of children with intellectual disability are discussed and common problems of being the parent of a child with intellectual disability are presented. In the last section, how the parents of children with disability cope with this situation is presented by examining the different factors in coping. Current studies in Turkey and findings in international research studies are also mentioned.

Understanding Intellectual Disability (ID)

Definition of Intellectual Disability

The essential characteristics of intellectual disability (intellectual developmental disorder), according to the DSM-5, are “onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains” (APA, 2013, p. 33).

According to DSM-5, there are three criteria that must be met to be diagnosed with intellectual disability (intellectual developmental disorder). First one is that onset of the disorder must be during the developmental period (APA, 2013). The second criterion is the deficits in intellectual functions, such as reasoning, planning, problem-solving, abstract thinking, judgment, academic learning, learning from experiences and practical understanding affirmed by both clinical assessments and standardized, individualized intelligence testing (APA, 2013). The last criterion is the adaptive deficits limiting the functioning in one or more activities in daily life, such as communication, social participation, independent living, and across multiple environments such as home, school, work and recreation (APA, 2013). Consequently, a diagnosis of intellectual disability should be made only when there is a deficit in not only intellectual functioning but also adaptive behavior functioning (Sattler & Hoge, 2006).

According to the definition of AAIDD (American Association of Intellectual and Developmental Disabilities), intellectual disability causes significant limitations in both intellectual functioning and adaptation behaviors in three different areas named as cognitive, social and adaptive skills (AAIDD, 2010). Besides, the disability starts before the age of 18. This means that people who have brain injury or disease in their later life and as a result have deficits in intellectual and adaptive skills are not in the category of intellectual disability (Oltmanns & Emery, 2012). It indicates that intellectual disability should be understood as who they are, not as something happening to them (Oltmanns & Emery, 2012). The following five assumptions are essential to the application of this definition are shown in Table 1:

Table 1: Assumptions regarding with the Application of the Definition of Intellectual Disability

1) “Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.
2) Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3) Within an individual, limitations often co-exist with strengths.
4) An important purpose of describing limitations is to develop a profile of needed supports.
5) With appropriate personalized supports over a sustained period, the life functioning of the person with intellectual disability will improve.”

Source: Retrieved from http://www.aaidd.org/intellectualdisabilitybook/, 2013.

Main Features of Intellectual Disability

The features of intellectual disability change according to the degrees of impairment. According to DSM-5, there are four categories of intellectual disability named mild, moderate, severe and profound which are categorized according to intelligence quotient scores (APA, 2013).

Adaptive behaviors are parallel to the classification system for intelligence level in DSM-5 (Sattler & Hoge, 2006). The system organizes developmental stages and level of intellectual disability, stresses on sensorimotor skills, language and communication learning, vocational skills and level of self-support (Sattler & Hoge, 2006).

Children with intellectual disability have difficulty not only in intellectual but also adaptive domains. They show slower rate of cognitive development, limited expressive and receptive language skills, short attention span, limited experiential background, distractibility, concrete and literal understanding (Sattler & Hoge, 2006).

Moreover, they are more likely to reach developmental milestones later than their peers. They generally have difficulty in motor coordination, remembering things, understanding social rules, thinking logically and solving problems (Sattler & Hoge, 2006).

Table 2 shows how adaptive behaviors, language and communication skills, motor skills, self-help behaviors and vocational skills vary according to the level of intelligence based on IQ scores:

Table 2: Adaptive Behaviors, Language and Communication Skills, Motor Skills According to the Age of Children with Intellectual Disability

Level	Preschool Age Birth to 5 years	School Age 6-21 years	Adult Over 21 years
Mild (IQs= 50-55 to 70)	Develop social and communication skills, often not diagnosed until school age Motor coordination is slightly impaired	Can learn up to about the 6th grade level by late teens Needs special education Particularly at secondary-school age levels, Can appropriate learn social skills	Can achieve social and vocational skills with proper education and training Frequently needs guidance when under serious social and economic stress
Moderate (IQs=35-40 to 50-55)	Can talk or learn to communicate Poor social awareness Fair motor development May profit from training in self-help Can be managed with moderate supervision	Can learn up to about 4th grade level by late teens if given special education May learn to travel alone in familiar places	Can contribute to self-support by performing unskilled or semiskilled work under sheltered conditions Needs supervision and guidance when under mild social or economic stress
Severe (IQs= 20-25 to 35-40)	Poor motor development Minimal speech Unable to profit from training in self-help skills Few or no communication skills	Can learn to speak or communicate Can learn simple health habits Cannot learn functional academic skills Can profit from habit training	Can contribute partially to self-support under complete supervision Can develop self-protection skills to a minimal useful level in a controlled environment
Profound (IQs<20 to 25)	Extremely limited in motor development and in all cognitive areas Likely needs nursing care	Some motor development Limited communication skills, Cannot profit from training in self-help skills Cannot learn academic skills Need total care	Can achieve some motor and speech development Totally incapable of self-maintenance Needs complete care and supervision

Source: Sattler & Hoge, 2006, p.433.

Prevalence of ID

Every culture feels distress from the burden of having children with intellectual disability which is seen approximately 2 or 3% of the population in developed countries and to a degree higher in developing countries (Azar & Badr, 2010).

According to the Turkey Disability Survey (DIE, 2002), population of people who are defined as mentally disabled was 331,043 individuals. This population consisted from 199,028 males and 132,215 females. It showed that there were more males than females with intellectual disability in Turkey. Moreover, there were more people with intellectual disability in rural area than urban ones (DIE, 2002). This finding is parallel to the study in which was advocated that intellectual disability is more prevalent among people from lower socioeconomic status (Mash & Wolfe, 2002).

When looking at the statistics of students in inclusive practices with mild intellectual disability, it is known that there are 2,771 individuals (1,018 female, 1,753 male) (Education Reform Initiative, 2011). It shows that 25.5 % of general population of students in inclusive practices in Turkey is students with mild intellectual disability.

Diagnosis of Intellectual Disability in Turkey

In Turkey, disability level in mental, psychological and personality disability is determined by functioning level of individual, not existence of symptoms (Official Gazette, 2010, no. 27787).

In childhood, intellectual functioning is not assessed with IQ level, but with limitation and difficulty in social activity and participation by clinical assessment with the participation of family and the child (Official Gazette, 2010, no. 27787). For clinicians, it is important to make “family-centered functioning assessment” to understand the child within the social and family context the child lives in (Official Gazette, 2010, no. 27787). In order to increase validity and reliability of clinical assessment, cognitive parts of standard tests are also used.

As assessment tools, tests with high validity, reliability and assessing functioning of individuals are preferred (Official Gazette, 2010, no. 27787). With these tests, IQ level is determined and related disability level (shown in the Table 3) is given to the individual (Official Gazette, 2010, no. 27787). Examples of these tests are; Wechsler Intelligence Scale for Children (WISC-R), Bayley Scales of infant development, Pediatric Evaluation of disability Inventory (PEDI), Peabody Picture-Vocabulary Test, Stanford Binet Intelligence Test, Vineland Adaptive Behaviors Scale, Learning Disability Scales, Ankara Developmental screening Inventory (AGTE), and Denver II Developmental Screening Inventory (Official Gazette, 2010, no. 27787).

According to the degree of intellectual functioning deficiency, the individuals are given a “disability level” (See Table 3).

Table 3: Disability Level According to the Level of Intellectual Functioning

A- Intellectual functioning deficiency	Disability Level
1- Border intellectual capacity (IQ: 70-80)	25%
2-Mild (IQ: 50-69)	50%
3- Moderate (IQ: 35-49)	70%
4- Severe (IQ: 20-34)	90%
5- Profound (IQ: below 20)	100%

Source: Official Gazette, 2010, no. 27787.

There are some legal procedures to get a diagnosis with intellectual disability in Turkey. Intellectual disability can be diagnosed in two important institutions in our country. First institution is the state or university hospitals where intellectual disability is diagnosed in medical perspective. These hospitals are operating as a branch of the Turkish Ministry of Health and they provide a committee report which shows the diagnosis of the children (Sakız, 2011). By getting medical report, people can be eligible to receive special education and some social services (Sakız, 2011). To have this right and benefit from these services, the percentage of the disability must be over a defined number (Sakız, 2011). For people with mild intellectual disability, the disability percentage must be over 20. With this percentage of disability in medical report, people might apply to special education.

After the committee gives the “medical report” of the disability, the family should apply to a “guidance and research center” in their district which is the second institution in getting diagnosis of the children. These centers operate as a branch of the Turkish Ministry of Education (Sakız, 2011). In these centers, the child is subjected to different standardized tests according to the diagnosis written in his or her medical report. The performance of the child is taken with regard to educational, self-care, language, social living skills and psychomotor skills. The test results and performance observations are combined and the educational report of the disability is prepared. But the main purpose of guidance and research centers in Turkey is to refer people having special needs to the institutions where they receive special education (Sakız, 2011). Besides, guidance and research center provides an educational plan and this plan should be followed by the school and special education center where the child is educated (Sakız, 2011). It is important to emphasize that valid medical report does not necessitate that the person can benefit from the special education because last decision is made by guidance and research centers where educational assessments are made.

With this educational report given by guidance and research center, children with mild intellectual disability are generally sent to inclusive classrooms. When a child with special needs is sent to an inclusive educational setting, individualized education plan (IEP) is prepared according to the educational and developmental needs of children (Sakız, 2011). The IEP is evaluated by the IEP committee at the end of each semester (Sakız, 2011).

Probable Causes of Intellectual Disability

The causes of intellectual disability vary and most of its causes are not clear yet. But the most known causes of this disability can be gathered in the headings of inheritance or environmental, genetic, neurobiological, social and psychological factors. These probable causes of intellectual disability will be mentioned next in detail.

Inheritance and the Role of the Environment

According to research studies, a genetic or environmental cause is known for nearly two-thirds of people with moderate to profound mental retardation while only quarter of those causes are known for mild intellectual disability (Mash & Wolfe, 2002).

Some factors occur before the birth (prenatal) as it is seen in all genetic disorders. Other causes can be birth-related called perinatal traumas like prematurity or lack of oxygen at birth (Mash & Wolfe, 2002). Furthermore, last types of causes stem from factors occur after birth such as inflammation of brain lining and head trauma (Mash & Wolfe, 2002).

In order to understand different causes of intellectual disability, two-group approach divided causes into organic and cultural-familial group (Mash & Wolfe, 2002).

In the organic group, strong biological factors are involved whereas in the cultural- familial group causes are still not very well known (Mash & Wolfe, 2002). According to the studies, up to 75 % of the normal intelligence is attributed to genetic factors but research studies do not identify which extent of genetic factors contribute to cultural-familial group (Oltmanns & Emery, 2012). Nevertheless, primary suspects are environmental and situational causes which are poverty, poor nutrition, parental psychopathology, and inadequate child care (Mash & Wolfe, 2002).

Family history of children has an important role in intellectual disability. Data shows that the chance of child having intellectual disability increases geometrically if both parents have normal IQ but one parent has a sibling with intellectual disability (13%) (Mash & Wolfe, 2002). If one parent has intellectual disability, the chance of child having intellectual disability increase is 20 %. But the biggest probability of increase is shown (42%) when two parents of child have intellectual disability (Mash & Wolfe, 2002). [In Table 4, mental retardation (MR) was used for intellectual disability but the recent name of this disability is intellectual disability or intellectual developmental disorder.]

Table 4: Organic and Cultural- Familial Causes of Intellectual Disability

	Organic	Cultural- Familial
Definition	Clear organic cause of MR	No obvious cause of MR Sometimes other family members has MR
Characteristics	More prevalent in moderate, severe and profound MR Nearly equal rates across all ethnic and SES level More often associated with other physical disabilities	More prevalent in mild MR Higher rates within minority groups and low SES groups Few associated physical and medical disabilities
Causes	Prenatal (genetic disorders, accidents in womb) Perinatal (prematurity, anoxia) Postnatal (head trauma, meningitis)	Polygenic (i.e, parents of low IQ) Environmentally deprived Undetected organic conditions

Source: Mash & Wolfe, 2002, p.245.

Genetic and Constitutional Factors

Intellectual disability can be caused by genetic abnormalities, genetic mutation or chromosomal deviations. In chromosomal abnormalities, Down syndrome, Fragile X syndrome, Klinefelter’s syndrome, Turner syndrome; in non-chromosomal genetic disorders, Rett syndrome, Prader- Willi syndrome, William syndrome and Angelman syndrome will be explained. In single gene condition, phenylketonuria (PKU) will be mentioned.

Chromosomal Abnormalities

Chromosome abnormalities are the most common cause of severe intellectual disability (Mash & Wolfe, 2002).

Down syndrome (Trisomy 21)

Down syndrome is the most common disorder stemming from such abnormalities (Mash & Wolfe, 2002). This syndrome has different physical characteristics such as small skull, a large tongue, almond-shaped eyes with sloping eyebrows, a flat nasal bridge, broad, square hands (Mash & Wolfe, 2002). Furthermore, people with Down syndrome have physical disabilities and limited speech (Oltmanns & Emery, 2012). The cause of Down syndrome is an extra gene from chromosome 21 and is associated with the maternal age (Oltmanns & Emery, 2012). When the age of mother increases, the probability of having a child with Down syndrome also increases (Oltmanns & Emery, 2012). Generally individuals with Down syndrome can function within moderate to severe level of intellectual disability and it is shown that through intensive intervention, they can function independently and reach higher school achievement (Oltmanns & Emery, 2012).

Fragile-X syndrome

It is the most common cause of inherited intellectual disability (Mash & Wolfe, 2002). Fragile- X syndrome is transmitted genetically by the mutation in FMR1 gene and diagnosed by break on one arm of X sex chromosome (Oltmanns & Emery, 2012). Children with Fragile-X syndrome have large forehead, a prominent jaw, low, protuberant ears (Mash & Wolfe, 2002). Generally individuals with Fragile-X syndrome have mild to moderate intellectual disability and may have Learning Disability and Attention Deficit Disorder. The majority of affected males have unusual social and communication pattern which is accompanied with shyness and poor eye contact (Mash & Wolfe, 2002).

Turner Syndrome (XO)

This disorder includes growth retardation and when it is not treated, it causes infertility and having height of 135-150 cm (Ergun, 1999). In this syndrome, females are missing their second X chromosome (Mash & Wolfe, 2002). People with turner syndrome have generally normal IQ and their intelligence varies from normal to low level (100-70 IQ) (Ergun, 1999). Turner Syndrome is characterized by immature interests, overconformity, concrete thinking and immaturity (Ergun, 1999).

Klinefelter’s Syndrome (XXY)

This syndrome is seen in males due to an extra X chromosome (Ergun, 1999). It is characterized by reduced body and facial hair, infertility, language and speech difficulties, and mild intellectual disability (Sattler & Hoge, 2006). Individuals with Klinefelter’s syndrome have a tendency to have antisocial behaviors, alcoholism and aggressiveness (Ergun, 1999).

Non-chromosomal Genetic Disorders

Rett Syndrome

“Rett syndrome is caused by a genetic mutation that affects brain development, primarily in girls” (Sattler & Hoge, 2006, p.434). This syndrome is characterized by developmental plateau and then regression which begins about in first 6 to 18 months of the life (Ergun, 1999). Because of progressive loss of hand movements and beginning of hand wringing, individuals with Rett syndrome have autistic-like behaviors (Sattler & Hoge, 2006). It leads to severe to profound intellectual disability (Ergun, 1999).

Prader- Willi Syndrome

It is a genetic disorder leads to short stature, mental retardation or learning disability, low muscle tone, incomplete sexual development and involuntary urge to eat constantly (Mash & Wolfe, 2002). Children with Prader- Willi syndrome need fewer calories than normal to have an appropriate weight or else, they can be obese easily (Mash & Wolfe, 2002). Obesity is the most common problems in adolescents with Prader-Willi Syndrome because of hyperphagia which means excessive hunger or increased appetite (Lowe-Greenlee, 2010).

Angelman Syndrome

Angelman syndrome is related to moderate to severe mental retardation (Mash & Wolfe, 2002). Individuals with Angelman syndrome have awkward gait, jerky movements, absence of speech, open-mouthed expression (Mash & Wolfe, 2002).

William Syndrome

It is a rare neurodevelopmental disorder which has genetic origin (Ergun, 1999). This syndrome causes severe to mild intellectual disability and deficits in cognitive-linguistic abilities (Ergun, 1999). Moreover, individuals with William syndrome have abnormal motor coordination, difficulty in fine motor and gait, and they generally experience high anxiety, sensitivity and negative mood (Ergun, 1999).

Single- Gene Conditions

Genetically based metabolic defects also affect intelligence and cognitive functioning (Mash & Wolfe, 2002). It is also known as inborn errors of metabolism (Mash & Wolfe, 2002). It is seen in 3-7 percent of situations in severe intellectual disability (Mash & Wolfe, 2002). One of the best known single gene conditions is phenylketonuria (PKU). PKU causes brain damages, seizures, mental retardation, and hyperactivity (Mash & Wolfe, 2002). But screening infants at birth for presence of any defect can prevent PKU with restricted diet (Mash & Wolfe, 2002). It shows how environmental interventions, in this case restricted diet, can have an influence on genetic disorder as in the case of PKU.

Neurobiological influences

Infectious diseases sometimes are the cause of intellectual disability. During pregnancy, at birth or after birth and in early childhood, exposure to some infection or toxins can affect intellectual abilities negatively (Oltmanns & Emery, 2012). For instance, rubella which is also called German measles can produce few symptoms in mother but this viral infection may cause intellectual disability and even death in fetus (Oltmanns & Emery, 2012). Syphilis, genital herpes, scarlet fever, mumps and tuberculosis of nervous system may also cause intellectual disability through transmission from mother to fetus (Mash& Wolfe, 2002).

Meningitis which is an infection of meninges and encephalitis, infection of brain can also produce permanent damage in the brain development and might cause intellectual disability (Oltmanns & Emery, 2012).

Prenatal, perinatal or postnatal exposure to toxic substances increases the risk of intellectual disability at children (Oltmanns & Emery, 2012). One of the most detrimental substances to fetus development is alcohol during pregnancy which leads to” Fetal Alcohol Syndrome” in children (Sue, Sue, Sue, & Sue, 2013). This disorder is characterized by facial abnormalities, retarded growth, cognitive impairment (Sue, et al., 2013). Children having fetal alcohol syndrome have difficulty in working memory, attention, learning, executive functioning and have intellectual functioning ranging from mild intellectual disability to normal intelligence (Sue, et al., 2013; Oltmanns & Emery, 2012).

Environmental toxins are also detrimental for fetus development of brain (Oltmanns & Emery, 2012). Mercury poisoning and lead poisoning may produce physical, emotional and intellectual impairment in children (Oltmanns & Emery, 2012). Furthermore, X rays and exposure to some drugs in prenatal stage can have a risk for fetal development (Mash & Wolfe, 2002).

Social and psychological factors

Environmental factors such as deprived emotional and physical care, lack of stimulation of infants and other disorders can affect intellectual ability of children but these psychosocial factors are generally indirect and unshown because being situated in different degrees of family and individual lives as well as different shared and unshared environment (Mash & Wolfe, 2002).

Impoverished environments do not have enough stimulation which challenges the intellectual skills of children (Oltmanns & Emery, 2012). Studies of adopted children indicated that children separated at birth from unresponsive and impoverished environments achieved at least 12 points higher than their biological mother’s IQ level (Oltmanns & Emery, 2012).

Moreover, children who raised by parents with mild intellectual disability start their lives with less challenging environments to increase their intellectual abilities but they also contribute to generational pattern of lower intelligence (Sue, et al., 2013).

Common Reactions of Parents of Children with Intellectual Disability

In this section, experiences of parents from the time that they recognize that their baby is not typically developing to their acceptance of the child's disability will be explained. There are common reactions before learning and after learning to have a child with intellectual disability. Parents have mixed emotions after finding out the disability of their children and these reactions can be group under three headings named as primary, secondary and tertiary reactions (Bıçak, 2009; Sen & Yurtsever, 2007). By considering these three main reactions, different kinds of stresses and needs of children which come out during different stages of development are mentioned in order to understand the situation parents of children with intellectual disability live in.

Prior Knowledge about Disability in Prenatal Period

Before the birth of their children, most parents do not have enough knowledge about disabilities. They generally have stereotypes and prejudices toward disability. In prenatal period, parents worry more about having a child with a disability, especially when they know other families whose children have disabilities (Seligman & Darling, 2007). Prospective parents fantasize about what their babies would look like. They have different knowledge, expectations and dream before the baby is born (Seligman & Darling, 2007). Because parents always expect a "normal" baby, they are not prepared to live with a baby having a disability.

For most cases, parents recall the name of a disability from a terrible picture depicted a disabled child, so they face with the disability in limited and negative ways (Seligman & Darling, 2007). With advanced technology, it becomes possible to diagnose childhood disorders before the baby is born. It is also possible that parents show positive reactions after the birth to understand that their children have less severe impairment (Seligman & Darling, 2007). Moreover, it can be advantage for families who learn the disability of unborn children earlier to adopt their life and prepare for themselves according to the needs of children with special needs.

Early Reaction to the Diagnosis

When a chronic illness or developmental disability comes up in a family, there is a period of disequilibrium and adjustment in order to maintain normalization in within family atmosphere (Seligman & Darling, 2007). However, because every family's uniqueness and complexity, the impact of having a child with disability is different so, the stages of grief may be applied in a flexible manner (Seligman & Darling, 2007). Stages can recur as new milestones or new crisis occurs. For instance, when the child with intellectual disability reaches the puberty period, the family can face new problems in controlling the emotions of their children although they have not dealt with these problems in childhood of their children.

According to stage theory, there are three situations in the group of primary reactions. These reactions are shock, denial, suffering and depression (Sen & Yurtsever, 2007).

After the baby with disability is born, common reaction for most of the parents is shock. Because parents are more vulnerable during postpartum period, they do not believe that their children could be treated (Seligman & Darling, 2007). In order to build emotional bounding, there should be some interaction between the parent and the child. But in the cases of babies with disabilities, there are few responses from babies to their parents which affect emotional bounding because parents are not rewarded by baby's responses (Seligman & Darling, 2007). For instance, the child's appearance, unpleasant crying, life-threatening conditions, feeding difficulties or prolonged hospitalization hinder parent-child bounding to be built (Seligman & Darling, 2007).

Also, expression of grief is very individualistic and each parent may react to the disability in different ways. While the mother is overwhelming with grief, the father might be stoic (Seligman & Darling, 2007). Furthermore, one reaction can be dominant while other reactions are present at different times toward disability (Seligman & Darling, 2007).

In birth situation, even for the parents who are ready for the disability, it can be disastrous to realize atypical events just after the birth. Generally meaninglessness and powerlessness are experienced by parents of children with disabilities (Seligman & Darling, 2007).

After shock, denial stage starts because denial is an unconscious coping strategy in order to avoid excessive anxiety (Seligman & Darling, 2007). In denial stage, parents cannot accept the disability of their children and parents who cannot go on to the next stage and generally ask why this event happens to their family (Köksal, 2011).

In early stages, denial may protect parents from anxiety but when it continues, it prevents parents to find realistic solutions for the benefit of the child (Seligman & Darling, 2007). When denial stage lasts for longer period, the child with disability may be pushed beyond his or her capabilities, or parents are looking forward to disprove the diagnosis of the child. Severity of denial may change according to the parents' psychological endurance, the severity of disability, and types of support the family receives (Seligman & Darling, 2007).

Reactions mentioned above are experienced when the diagnosis is made just after birth. But sometimes it is not possible to diagnose disability shortly after the birth. For instance, intellectual disability in children can appear or be diagnosed in infancy or childhood period (Seligman & Darling, 2007). When the definition of "normal" child turns into "disabled" one, adjustment of parents to the situation becomes more problematic (Seligman & Darling, 2007).

But in some cases, parents feel relief after receiving the correct diagnosis. They suspect from some anomalies and delayed development in their children before the doctor gives diagnosis. In a study of families whose children have intellectual disability, it is seen that most families experience little or no worry when they get diagnosis (Seligman & Darling, 2007). Even though they get relaxed after the uncertainty disappears, different kinds of stresses will come out in different stages of development. For example, the needs of children in childhood is different from the needs of children in adolescence despite they have the same disability.

Having a child with disability means the disappearance of parents' expectations of their ideal child (Sen & Yurtsever, 2007). Having a child with disability creates similar feeling with the feeling after loss of a loved one, so parents of these children experience grief and suffering with the same emotion (Vural-Batık, 2012). They experience disappointment and sense of loss after learning the disability their child has (Trute, Benzies, Worthington, Reddon, & Moore, 2010). In some aspects, parents lose the ideal child they have expected before the birth. Depression starts at the end of the suffering process (Sen & Yurtsever, 2007). Generally most parents of children with special needs feel that they do not have strength to fulfill the responsibility of their children with disability so they feel depressed (Sen & Yurtsever, 2007). Because of the effects of suffering and depression, parents may avoid social contacts and experience withdrawal (Sen & Yurtsever, 2007). At this point, interpersonal stress comes out.

Interpersonal stress involves family members, teachers, friends and medical personnel of children with disabilities. With the increased stress, parents of children with disability might have difficulty in fulfilling the requirements of daily concerns and this can reflect on their interpersonal relationships with others poorly (Vural-Batık, 2012). Research shows that disability in children may contribute to the marital distress (Seligman & Darling, 2007). According to the studies about families whose children have disabilities, there is no significant difference between parents with disabled children and parents with the child without disability in regard to divorce rate (Seligman & Darling, 2007). Parents of children with disability are not more likely to divorce but they experience stress and marital dissatisfaction (Seligman & Darling, 2007). On the other hand, for some parents; relationship gets stronger because of increasing cohesiveness to cope with the stress coming from disability (Seligman & Darling, 2007).

According to Wickler (1981), stigmatized social interaction is one of the chronic stresses unique to families of children with intellectual disability. Because people generally feel uncomfortable to interact with children with intellectual disability, parents of these children should become advocates for their children. Parents of children with ID can face murmurs of pity, hostile attitudes, judgmental opinions and suggestions when they go out with their children. It is a difficult period for families "goes public" to meet other people (Seligman & Darling, 2007). As the discrepancy between the mental age and chronic age of children is becoming larger, the stress of the parents increases (Wickler, 1981).

After depression period, secondary reactions occur in parents of children with special needs. In secondary reactions, there are four reactions named as feelings of guilt, indecision, anger and shame (Sen & Yurtsever, 2007).

Guilt feelings generally come from parents' thinking that they cause their children to be disabled or due to their mistakes, they are punished by God (Sen & Yurtsever, 2007). The feeling of guilt helps parents keep their anger under control so they cannot anger at the child due to his or her disability (Sen & Yurtsever, 2007). While some parents can adapt the situation quickly, the others cannot which creates indecision in family (Sen & Yurtsever, 2007). Indecision may cause family members to blame or neglect each other. This can increase interpersonal stress in the family environment.

After indecision, anger comes out. Parents might show anger at God, or medical doctors not healing the child, or at spouse that are not producing healthy child or himself (Seligman & Darling, 2007). At this stage, existential stress may occur. The existential stress is related to family's ability to find an explanatory meaning from their experience with their children having disability. Existential questions such as "why me?, Why my family?" are observed more commonly in parents of children with disabilities (Seligman & Darling, 2007). It is possible to see the children with disability as mother's inadequacy, marriage failure or a divine gift (Seligman & Darling, 2007).

After anger, parents of children with special needs feel shame because they perceive their children as an extension of themselves and they may not want to be seen in society (Sen & Yurtsever, 2007).

The Need for Information and Looking for Interventions

Mostly, many parents of children with disabilities are just given diagnosis report. This means that it is only a label with limited information from professionals. The name of the diagnosis does not provide information for parents about the disability of their children. Because of this reason, parents continue to worry and wonder whether their children would be able to talk, walk, go to school and have an occupation or not. In other words, parents have lack of prognostic information about their children (Seligman & Darling, 2007). According to the study findings, information provided by professionals is more beneficial than emotional support and sympathy because parents of children with intellectual disability need on-going information in order to understand the meaning of the child's current situation (Seligman & Darling, 2007).

At this stage, first reaction in tertiary reactions, bargaining, is seen (Sen & Yurtsever, 2007). Bargaining stage is consisted of unrealistic expectations of parents and their effort to improve child's condition. Turning to religion or expecting a miracle to get rid of disability is commonly seen in bargaining stage (Seligman & Darling, 2007). According to the research study conducted by Poston and Turnbull, that disability of children is seen as a factor to elevate the level of spirituality among family members (Seligman & Darling, 2007). Poston and Turnbull (2004) defined spirituality as the area in life which consisted of the need to find meaning in our existence, the way that we respond to the sacred and the search for fulfilling the relationship between oneself and the others.

With the purpose of “fixing” the child with special needs, parents experience intellectual stress. Intellectual stress starts with the time that they get information about the child’s disability. While parents are searching for information about the etiology, prognosis and treatment of the disability their children have, they experience anxiety (Seligman & Darling, 2007). They make “doctor shopping” to find the best medical doctor who makes the right diagnosis and treatment, as well as behaves empathetic and responsive to parents (Seligman & Darling, 2007).

It is also stress provoking to think about different aspects of the child’s disability. Information about different treatments, their side effects, symptoms of decline or improvement increase the intellectual stress of parents (Seligman & Darling, 2007).

Information is excessively needed by parents of children with intellectual disability because these parents do not have chance to get benefit from other parents whose children do not have disability (Wickler, 1981). Due to these children’s special needs, parents should get specific information to care their children. Other parents of children with ID are not always beneficial because every child with intellectual disability has different severity and he or she is in different developmental transition. Furthermore, it is inadequate to get information at a one time since parents of children with intellectual disability need specific information to cope with different crisis situations (Wickler, 1981). They need information throughout life course of the child with ID.

When parents look for treatment programs, they have generally unrealistic expectations such as programs curing their children (Seligman & Darling, 2007). When the bargaining stage ends, parents stars to get information about their children and look for solutions for their problems (Sen & Yurtsever, 2007). After parents' feeling that life has lost its meaning, parents come to a turning point and get closer to accept the reality of disability (Seligman& Darling, 2007). When parents are able to discuss the child's disabilities, collaborate with professionals to make short and long-term plans, avoid being overprotective and use discipline without undue guilt and have personal interest unrelated to their child, they reach to acceptance stage (Seligman & Darling, 2007).

But acceptance does not mean that parents think that disability is not changeable (Seligman & Darling, 2007). Rather, parents accept that there is more to do for the benefit of child and what is done makes a difference in child's condition (Seligman & Darling, 2007). When parents accept that they cannot change the fact about the children with special needs, they transform their thoughts into action, adaptation starts because they believe that they can only change medical services needed for their children (Sen & Yurtsever, 2007).

Childhood of Children with Intellectual Disability

"Normalization" of the disability is the main feature of childhood period for families of children with disability (Seligman & Darling, 2007). In childhood, parents generally go back to their normal life and daily routines because of this reason, this period is called normalization. Parents start social activities which are paused after the birth of their children with disability. Mothers may want to continue their work life. There are general factors that include normalization. These factors are employment of either or both parents, adequate housing, sufficient economic resources to maintain daily life, leisure time, having appropriate medical services, access to educational placement for children with disability, social relationship with other families and friends (Seligman & Darling, 2007).

According to research studies, needs of parents of children with disability are met in higher amount in terms of respite care, counseling and family support services in preschool years and young adulthood (Seligman & Darling, 2007). On the other hand, in childhood period, the lowest percentage of services is given to the families of children with disability (Seligman & Darling, 2007). In this period, there are some difficulties which make harder going back to normal life. These are continuing medical care of children, special educational needs, behaviors problems and stigmatization of the children with special needs and financial burden.

Continuing Medical Care

Children with disability more frequently need medical care than other children do (Seligman & Darling, 2007). It is very problematic for families of children from low socioeconomic status in term of availability of medical services because disability is generally insuranced by public services not private ones (Seligman & Darling, 2007). Furthermore, when the medical care is available, it is hard to find a medical doctor who wants to treat a child with disability (Seligman& Darling, 2007).

Special Educational Needs

Special Education Legislation has mandated that children with disability are given free and appropriate public education in the least restricted environment (Seligman & Darling, 2007). However, because of many reasons such as fear, ignorance, limited knowledge and limited resources in school, many students with disability could not benefit from this legislation (Seligman & Darling, 2007). Because parents of children with disability do not know their legal rights, they could not question or challenge educators about this problem (Seligman & Darling, 2007). Another complaint is lack of coordination among teachers, principals, parents, school counselor (Seligman & Darling, 2007). Because regular classroom teachers are not well prepared for children with disabilities, they generally do not follow guidelines stated in Individualized Education Plan (IEP) (Seligman & Darling, 2007). Moreover, sometimes parents and school system cannot agree with the program or therapy the child with disability should take (Seligman & Darling, 2007). Because of these reasons, children with disability face difficulties while receiving special education services.

Behavior Problems

According to the studies conducted with children with intellectual disability, the main stressors related to medical care and management of the child are stated as behavior management problems and child's on-going dependence (Seligman & Darling, 2007). While the children with special needs are getting older, parents generally worry about the children's behaviors in public. When the behaviors of children become nonnormative and uncontrollable, the social participation of the family decreases because it is difficult for people from outside to understand the situation of children and it is hard to control behavior of children outside home (Seligman & Darling, 2007). Parents of these children generally try to explain the disability of child to the stranger, or move away from challenging and distressing situations.

Financial Burden

It is expensive for families of children with special needs because there are direct costs such as expenses for child care, medical needs and therapy and indirect costs such as lost work time and difficulty in career advancement (Seligman & Darling, 2007).

Stigmatization of the Child with Special Needs

Stigma is a sociological concept which is related to the value people place on social identities (Seligman& Darling, 2007). In order to describe a social identity as stigma, it must be recognition of difference based on distinguishing features and lead to devalue of the person (Seligman & Darling, 2007). Because of this, people who are stigmatized are exposed to prejudice, avoidance and rejection in society. Disability is seen in the category of stigmatization in which it was seen as visibileness, controllability and dangerousness (Seligman & Darling, 2007). To the extent people deviate from social norms of physical and mental perfection, they are more likely to be avoided, ridiculed and discriminated (Seligman & Darling, 2007).

Some disabilities are more likely to be stigmatized because they are discreditable due to their visibileness such as Down syndrome. People with discreditable disabilities and their families sometimes involve in “impression management” in order to be seen as “normal” (Seligman & Darling, 2007). In discreditable situations that are visible and obvious for other people, being seen as normal is not possible. When an individual with visible disability and nondisabled person come into contact, they act as if the disability does not exist because nondisabled person does not really accept the person with disability as more equal (Seligman & Darling, 2007). Due to this reason, close associates or families of person with disability are also stigmatized and be avoided, rejected as the disabled person did (Seligman & Darling, 2007).

As most studies show that stigmatization attitude does not only belong to lay people but also to professionals (Seligman & Darling, 2007). Because some professionals do not have direct experience with children with disabilities, they have difficulty in understanding the positive aspects of relationship between parents and children with disability (Seligman & Darling, 2007). According to the results of World Health Organization report, people in general from 10 different countries lack an understanding of the abilities people with intellectual impairments have (WHO, 2011).

Furthermore, professionals may feel inadequate while working with families of children with disability. One study about stigmatization toward disability demonstrated that there was a significant difference between professionals' and parents' responses to a questionnaire about the effect of the child with disability on family (Seligman & Darling, 2007). Parents of children with disabilities can be seen as very troubled, burdened, and extraordinarily brave (Seligman & Darling, 2007).

In childhood period of children with special needs, parents generally experience instrumental and emotional stress. Instrumental stress arises from tasks which are necessary integrate their children's care and treatment into the life of family (Seligman & Darling, 2007). Parents become the primary caregivers of their children and try to provide their needs and treatment program. They have to accommodate their daily routines and living styles to the needs of the child with special needs (Vural-Batık, 2012). But they also attend to the needs of other family members (Seligman & Darling, 2007). Instrumental stresses of parents whose children have disabilities are financial demands, determining division of labor at home, becoming aware of effect of disability on family members, continuing household chores besides of child caring (Seligman & Darling, 2007).

Prolonged burden of care also increases instrumental stress because as the children with intellectual disability grow up, they become more burdensome (Wickler, 1981). Prolonged burden of dependency and care continue throughout the life of the children.

Parents of children with disabilities experience lack of sleep, excessive worry and anxiety, loss of energy which result from excessive demands of caregiving (Seligman & Darling, 2007). Moreover, ambiguity and uncertainty of the disability increase the emotional stress of parents.

In order to meet the needs of children with special needs, mothers take more responsibility and spare more time to caring of their children than fathers do. Therefore, the mother who takes whole responsibility of caring the child with disability is getting alienated or isolated from her husband and other children (Köksal, 2011). According to the research study about perception of health of parents whose children have intellectual disability, mothers take more responsibility for childcare and have more pressure than fathers (Köksal, 2011).

According to the findings of the study which investigated the depression level of mothers whose children had developmental disorder or intellectual disorder, mothers have higher level of depression than fathers have (Köksal, 2011). As the study conducted by Azeem et al. (2013), the depression and anxiety level of mothers of children with intellectual disability were higher than the fathers of these children. The level of depression in these mothers is positively related with inefficient coping strategies, lower level of social support of these mothers and the factor of having more than one disabled member in the family (Köksal, 2011).

According to the research studies for mothers and fathers whose children are diagnosed with mild intellectual disability, mothers are more likely to look for external help, turn to religion, acceptance and cognitive configuration (reframing) as coping strategy (Köksal, 2011). On the other hand, fathers are found to use active planning, denial and abstraction as coping strategy. Besides, mothers are getting more social support than fathers and there is a negative relationship between mothers' psychological symptoms and perception of social support they take (Köksal, 2011).

According to the studies, mothers and fathers cope differently with the condition of their children with disability. Mothers have been found to use broader range of coping strategies than fathers which consisted from cognitive and interpersonal coping focusing on family responsibilities and childcaring (Azar & Badr, 2010). While mothers are consulting with the medical team, fathers prefer to use cognitive behavior styles about work and family duties (Azar & Badr, 2010). But there are also studies which indicated that fathers' coping behaviors do not differ from mothers' behaviors because fathers might be traumatized as much as mothers (Azar & Badr, 2010).

Adolescence and Adulthood of Children with Special Needs

Responsibilities and role of parents of adult children with intellectual disability continue until the parent cannot satisfy the needs of their children due to illness or death (Rowbotham, Carroll, & Cuskelly, 2011). This situation is different from parents of typically developing children because these people's parent role decreases as the children become mature. Role strain more likely occurs in mothers of young children with intellectual disability than fathers as studies showed (Rowbotham, Carroll, & Cuskelly, 2011). This results from unequal childcare responsibilities between mothers and fathers in families of children with both normal development and intellectual disability. Greater the childcare responsibilities and work, the more chances of conflict between childcare responsibilities and employment are observed (Rowbotham, Carroll, & Cuskelly, 2011). But studies showed that working outside home is a more protective factor for mothers of children with intellectual disability in terms of their returns well-being (Rowbotham, Carroll, & Cuskelly, 2011).

How to Cope with These Situations?

Thus far, common reactions of parents toward responsibility of having a child with special needs are explained according to different stages of reactions and development. In this section, ways of coping and factors that increase resiliency will be mentioned. Studies about coping are also demonstrated.

Lazarus and Folkman defined coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Bayraklı & Kaner, 2012). There are two types of coping style named problem-focused and emotion-focused coping. Emotion-focused coping supports that threating situations cannot be changed and manage the negative emotions coming from the stressful situations. In contrast to emotion-focused coping, individuals using problem-focused coping have behavioral efforts in order to control and change the stressful situation (Bayraklı & Kaner, 2012). Problem-focused coping is a protective factor because people using problem-focused coping have more effective ways to respond to the stressful situations.

In order to have adaptive coping with serious negative events, meaning is found through recognition of the advantages and personal benefits of the challenging event. Therefore, the challenge is redefined and emotional effects of the negative event are minimized (Trute, Benzies, Worthington, Reddon, & Moore, 2010). As the reality of the event remains the same, perceived meaning of the situation becomes less hurtful (Trute, Benzies, Worthington, Reddon, & Moore, 2010).

Positive emotions are seen as the tolerable factors and experiencing positive emotions can help increase psychological coping resources (Trute, Benzies, Worthington, Reddon, & Moore, 2010). Trute, Benzies, Worthington, Reddon and Moore (2010) conducted a longitudinal study to explore the influence of cognitive appraisal and psychological coping resources. The study showed that when mothers have negative appraisal of family impacts of childhood disability, it led to family limitations or little problems in family adjustment. If the level of positive appraisal the mothers can recognize from the childhood disability is higher and she carries this appraisal to the family, the overall family adjustment is also higher (Trute, Benzies, Worthington, Reddon, & Moore, 2010). When there is a chronic illness in a family, family generally uses three coping strategies in order to sustain family life: retaining family integration, cooperation and optimistic aspects of the situation, maintaining social support, psychological stability and learning medical condition through communicating with other parents and consulting with medical staff (Azar & Badr, 2010).

Findings suggested that optimism and positive appraisal of mothers to the childhood disability of their children are associated with the overall adjustment of the family (Trute, Benzies, Worthington, Reddon, & Moore, 2010).

Researchers conducted a study to inquire the effects of parents' personality and having children with developmental disorders on their coping styles (Köksal, 2011). Findings of this study showed that parents generally used emotion- focused coping than problem-focused coping strategies and having neurotic factor in personality predicted the type of coping strategies parents use (Köksal, 2011).

Resilience

Generally most families experience some kind of stress and worry when they learn that their children have a disability (Seligman & Darling, 2007). But this does not mean that all families with disabled children experience negative feelings and stress. Some families can adapt and do well even in the adversity of disability while some experience turmoil and struggle (Seligman & Darling, 2007). According to Vural-Batık (2012), some parents approach the problematic situation in more constructive ways, face the reality and look for interventions and services for the benefits of their children. While some parents express a positive attitude toward life, other parents of children with disability do not utilize their resources and cannot manage the situation and experience dissatisfaction and sadness in their life (Gardner & Harmony, 2002). Some research studies showed that there was no difference between the level of stress, anxiety and burn out levels in mothers with and children without disability (Bayraklı & Kaner, 2012). It is also important to take other risk factors that affect family atmosphere into the account such as poverty, family violence, and lack of parenting skills, work-related stress, drug abuse and alcoholism. These factors can hinder the family to build their resilience toward the stress of having a child with disability (Seligman & Darling, 2007).

The concept of “resilience” means that not all people react to a negative event as predicted despite of the accumulation of risk factors. Resilient families try to find the meaning in the presence of adversity. They actively try to seek out resources and opportunities to cope with the disability of the children in the family (Seligman & Darling, 2007). It shows that even in the face of chronic and severe illness, there are ways to deal with stress.

Studies conducted between 1960s and 1980s indicated that having a member with intellectual disability in family created distress and problem. On the other hand, study findings between 1980s and 1990s demonstrated that people having children with intellectual disability are able to manage the situation and live happily and successfully (Gardner & Harmon, 2002). In recent research studies, it has been stressed that having a child with disability does not necessarily bring about high level of stress and these families can also recognize the positive impacts of having children with disability (Trute, Benzies, Worthington, Reddon, & Moore, 2010).

It shows that literature about parents of children with intellectual disability have turned from deficit-based thinking to strength-based thinking (Gardner& Harmon, 2002). Because the more personally challenging the event is, the more chances are found for personal growth (Trute, Benzies, Worthington, Reddon, & Moore, 2010). According to the studies about resilient mothers, social support and coping strategies are the two important protective factors (Bayraklı & Kaner, 2012).

Social Support

Social support can be defined as the belief that the person is loved, accepted, appreciated and one part of interpersonal support network (Köksal, 2011).

Social support is a mediating or protective factor in providing the needs of a stressful event. Because we are social beings, having a social support can intervene between a stressor and a stress reaction as a buffering factor (Seligman & Darling, 2007). For coping of threats toward well-being of parents whose children have disability, social support is very important factor (Köksal, 2011). Research shows that having a supportive social network leads to increased well-being, positive parental attitudes, improved child behavior and better parent-child relationship (Seligman & Darling, 2007). Social support is an important factor which makes adaptation of living with a disability easy and decreases the stress level of parents of these children (Köksal, 2011). Although there are similarities across cultures with regard to the stress of caring a child with disability, there are also differences about stigma associated with having a child with disability, and availability of support in the community (Azar & Badr, 2010). Research studies about social support have indicated that when social support of parents of children with disabilities increases, the level of hopelessness and stress decrease but the level of well-being and adaptation increase (Köksal, 2011). The isolation experienced by most families of children with disability increases the importance of social support. This isolation comes from lack of being understood and accepted, emotional and physical exhaustion of the family and special needs of children with disability (Seligman & Darling, 2007).

Social support can be in form of one-to-one or group support. Also, social support can come from informal resources such as other families, friends, neighbors while formal support can be obtained from professionals (Seligman & Darling, 2007). According to the result of studies, it was found that implementation of psychological support and receiving counseling services increase the optimism level of mothers of children with intellectual disability while decrease hopelessness level of these mothers (Vural-Batık, 2012). Besides, mothers involving in group counseling services mentioned that they took support from other mothers whose children also have intellectual disability and expand their network and overcame the feeling of loneliness (Vural-Batık, 2012).

Furthermore, research demonstrated that in the area of developmental disabilities, professional support is related to reducing parental stress (Lowe-Greenlee, 2010). Based on the results of a research study about parents of children with developmental disabilities, the relationship between child behavior and parental stress is found to decrease with professional support which includes parenting information and practical child caring aid, after controlling age, IQ and language development of children (Lowe-Greenlee, 2010). While coping with the stress coming from stigma or parent perceived difficulties in providing the special needs of children with developmental disabilities, professional support becomes necessary (Lowe-Greenlee, 2010). Research have showed that parents of children with intellectual disability need professional support in the areas of parent counseling, crisis support, support in obtaining medical health care services, information about disability of their children and extracurricular activities their children can attend (Lowe- Greenlee, 2010).

A study which compared the parents of children with intellectual disability and hearing disorder with regard to social support, stress and life satisfaction indicated that parents of children with intellectual disability had more stress, pessimism and perceived their children less capable (Köksal, 2011). However, parents of children with intellectual disability perceived their life satisfaction high and higher level of life satisfaction decreased the perceived stress in lives of parents

(Köksal, 2011). Also, life satisfaction level is predicted by having children with intellectual disability and insufficient social support system (Köksal, 2011).

In 2009, the study with mothers of children with disability in Kahramanmaraş Guidance and Research Center, in Mediterranean region of Turkey, showed that these mothers had higher level of trait anxiety and there was a negative relationship between social support and trait anxiety of these mothers (Coşkun & Akkaş, 2009). When the attainment level of parental education and family income increase, the level of trait anxiety decreases but however the level of social support of these mothers of children with disability increases (Coşkun & Akkaş, 2009).

According to the statistics in a study which investigated the difficulties of mothers of children with intellectual and physical disability experienced, 46.3% of these mothers feel uncomfortable toward the attitudes of society, 38.9% of mothers have difficulty in communicating with their neighborhood and 45.3% of mothers do not take any social support (Köksal, 2011). Meta-analysis of nine studies of parents of children with intellectual disability demonstrated that informal social support from family, friends and partners helps make family adjustment easier (Köksal, 2011).

As can be seen, having children with intellectual disability increases the level of stress but having social support helps decrease this stress. Although social support cannot solve the problematic situation, it helps decrease anxiety and hopelessness of parents and brings out new coping strategies and increase optimism (Köksal, 2011). On the other hand, the study conducted by Köksal (2011) demonstrated that there was no significant relationship between social support and parental stress because in that study social support was defined only as emotional support. But instrumental and information giving aspects of social support were not taken into consideration and these dimensions are important for parents of children with disabilities (Köksal, 2011).

Marital Quality

In research studies of resilience, supportive person in one's life is one of the factors that lead to resilience (Gerstein, Crnic, Blacher, & Baker, 2009). High quality marriage might be compensatory factor for parents with psychological distress. For married couples, their partners are one of the most important support resources (Köksal, 2011). Research studies indicated that having a healthy relationship with an intimate partner is related to decreasing parenting stress (Gerstein, Crnic, Blacher, & Baker, 2009). Furthermore, availability of a husband even when he does not take responsibility in caring is beneficial. For instance, a supportive husband is an indicator of a mother's sense of psychological well-being although he does not involve in caretaking (Seligman & Darling, 2007).

A research conducted in 2008 with the parents of children in "Training Application School" showed that 19.4% of parents of children with disability accuse each other for the disability, 18.5% of parents experience family conflict and 53.7 % of parents realized their relationship getting stronger among family members (Köksal, 2011). Study findings in parents of children with intellectual disability demonstrated that marital adjustment had effect on level of both paternal and maternal stress (Köksal, 2011).

According to research study by Şardağ showed that marital adjustment of mothers whose children had intellectual disability was predicted by intimate relationship support, optimistic attitude toward coping with stress and emotional support (Köksal, 2011).

Marital problems of parents of children with intellectual disability are seen to be related to negative experiences of changing relationship between partners. However, there are also studies which show that there is no difference between marital adjustment of parents of children with disability and other parents (Köksal, 2011). Furthermore, it has been supposed that having a child with disability can have positive contributions to the marriage of the parents (Köksal, 2011). The study by Köksal (2011) showed that perceived stress was not predicted by not only marital adjustment of parents of children with intellectual disability but also other parents of children without disability. When the marital adjustment of parents of children having intellectual disability decreases, parents perceive more stress in their lives (Köksal, 2011). In this study, marital adjustment was found to have positive effect on the psychological well-being of family.

In line with the research studies stated in literature about the families of intellectual disability, this study aimed at understanding the life experiences of mothers of children with intellectual disability. In order to expand the perspective of the study, the lives of the mothers were examined with regard to their daily life with their children, their mothering role, their social and marital lives, their expectations from the future and the positive aspects of having a child with disability.

CHAPTER III

METHODOLOGY

Research Design

Since this study aims at understanding the phenomenon of intellectual disability through the experiences of mothers who share their lives with their children having intellectual disability, qualitative approach will be used for data collection and analysis. Qualitative research provides understanding the meaning people have created about their own experiences and how they sense the world from their perspectives (Merriam, 2002). Maykut and Morehouse (1994) explained the qualitative data as the words which most people come to understand their situations. They also stated that people create their world with words; they explain themselves with words; they defend and hide themselves with words (Maykut & Morehouse, 1994). According to Maykut and Morehouse (1994), researcher should find patterns within those words and show them for other people to understand and also stay close to the world participants experienced.

For this reason, qualitative approach is appropriate for realizing how mothers of children with intellectual disability construct their world and give meaning their life experiences with their children.

Participants

In order to understand experiences of mothers whose children have intellectual disability, the data were gathered through in-depth interviews. Mothers of children with mild intellectual disability were chosen to control homogenization of sample and prevent different confounding factors due to spectrum of intellectual disability.

Another criterion for selecting mothers was that mothers of children must have been diagnosed at least three years with the aim of eliminating mothers who were still in denial stage. These children were given medical and educational diagnosis of mild intellectual disability through state and research hospitals and then guidance and research centers. Children of participants were between the ages of seven to fifteen. The children of these mothers were receiving special education services and they were all in inclusive educational settings in their school as well.

Ten participants, one of which was selected for pilot study before the interviews conducted, were selected from a public primary school and two different special education and rehabilitation centers in Kartal, İstanbul. These places were chosen because of their availability for data collection and convenience. For these ten participants, the mothers who attended the mother support group consisting of seven sessions in our school were selected. From this group, four mothers whose children were diagnosed with mild intellectual disability were voluntarily to participate in this study. One mother from this support group was selected for pilot study and the rest of the 3 mothers were selected for the interviews. Other 6 mothers were selected from our school and two different rehabilitation centers from our district Kartal.

Because some of participants were from the school, interviews were conducted with them in the counseling service. For other participants, a quiet room in special education and rehabilitation centers was used because it was convenient for mothers to conduct interview after they left their children to the school or rehabilitation center.

Appendix E shows demographic information of participants including age of mother, socioeconomic level (SES), educational level, occupation, number of children they had, diagnosis of children, sex of child, age of child, having kinship and name of the child. Additionally, Appendix I gave further information about the diseases the children in this study suffered from. All mothers and their children were given a pseudo name to increase confidentiality. In this part, participants were introduced by their demographic information as follows:

Selma is a housewife and 33 years old. She has two children and her oldest son, *Arda*, had mild intellectual disability and also diagnosed with Attention Deficit Hyperactivity Disorder (ADHD). Selma graduated from high school while her husband graduated from university. She has also 6 year-old son having no disability identified. In their family, her cousin has intellectual disability and Arda's uncle has physical disability. She has no kinship with her husband and she did not have any physical or medical problems during pregnancy. During interview, she was observed to be oversensitive about her son's disability and she was fighting for getting the legal rights of her son.

Necla is a housewife who is 38 years old. She had two children and her daughter, *Betül,* had mild intellectual disability and ADHD. Necla graduated from primary school while her husband graduated from high school. Her uncle's son had also intellectual disability. She had no kinship with her husband. Moreover, she did not experience any medical problems during her pregnancy. She seemed to be a touchy mother who was crying while remembering her daughter's disability and her life during interview. She mentioned her worries about the future of her daughter and looked depressed.

Neriman is a 43-year-old housewife. She has one child, *Ahmet* who has mild intellectual disability coming from his "maple syrup urine disease" (See Appendix I for further information about the disease). Neriman graduated from secondary school and her husband graduated from high school. She had kinship with her husband and they were cousins. They have also other cousins who have intellectual disability. Neriman looked very depressed about her son's disability and his medical survival psychologically affected her mother because her son had lots of physical problems before the diagnosis. During the interview, it was observed that she was trying to be strong despite her depressed mood. She was trying to get information about the education of her son.

Melike is 42 years old and housewife. Melike had two daughters and her second daughter, *Burcu*, has mild intellectual disability. Melike dropped out high school while her husband graduated from primary school. She had no kinship with her husband. Burcu's aunt has physical disability. Moreover, Melike has problems regarding the development of cerebellum and also has psychiatric problems. She seemed angry but at the sometime continually laughing during the interview. Even talking about sad memories, she seemed to be smiling. Her reactions were not consistent with her mimicry.

Mine is a 38-year-old housewife who has two daughters. Her second daughter *Canan* has mild intellectual disability while her other daughter has orthopedic and mild intellectual disability. Mine and her husband graduated from primary school. Mine's sister has also orthopedic disability. She has no kinship with her husband. Mine got information about her daughters' disability and she was trying to educate her children. She was diagnosis with major depression. Although she suffered from major depression, she had strengths to cope with this disability and accepted her condition.

Hediye is a 39-year-old housewife. She had two children. Her first child, *Doğukan* diagnosed with mild intellectual disability and ADHD. He has also new diagnosis “child psychosis”. Hediye and her husband graduated from high school. She did not have kinship with her husband. Hediye’s aunt has physical disability but she did not have what kind of a disability her aunt had. Hediye was talking with a voice which has no feeling. She was talking about her problems but she did not show any mimicry or feeling. She seems to be talking without emotions. She also mentioned that she could not cry for years since the diagnosis of her son. During mother support group sessions, she said that it was first time she cried after the diagnosis of her son.

Hande is 35 years old housewife. She graduated from primary and her husband graduated from secondary school. She has two daughters and her first daughter, *Nazlı*, has mild intellectual disability. Hande has kinship with her husband. They do not have any relatives with disability. Hande looked very relaxed and calm. She mentioned little information about her child’s disability and she did not show sadness about her daughter’s disability.

Filiz is 42-year-old housewife. She has three sons and *Mert* is her second son. He has mild intellectual disability due to his “hydrocephalia” (See Appendix I for further information about the disorder). She and her husband graduated from high school. She got divorced and she looked after her sons on by own. She did not have kinship with her husband. They do not have relatives with disability. During interview, she gave short answers and she did not seem to express her feelings very much.

Aylin is 56 years old and is a housewife. She had two children. Her son, *Utku,* was diagnosed with Down syndrome and he has mild intellectual disability. Aylin graduated from high school and her husband graduated from secondary school. Her husband died three years ago. She did not have any kinship with her husband. She was searching for her son's education and disability. Although she cried a lot during the interview, she tried to control herself and seemed strong.

All participants were housewives and except one participant, rest of the mothers had more than one child. The ages of mothers ranged from 33 to 56. Also, all participants have the experiences of living a child with intellectual disability more than three years. Participants SES level and education level were also different, so this fact enabled researcher enlighten the research study a lot.

Instrument

The aim was to understand having a child with intellectual disability from the perspectives of their mothers so face to face in-depth interviews were used with participants. Also, a demographic form was given before the interviews. Then, interview questions were discussed during the interviews (Also see Appendix B for Turkish Form of the Interview Questions).

English Form of the Interview Questions

1. How was your pregnancy?
   What were your expectancies about your baby during your pregnancy?
   How did you expect your mothering role during pregnancy?
2. When and how did you first realize that your child is different?
   How was the diagnosis process?
   How did you react when you learned the diagnosis of your child?

What did you know about this disability?

3. What do you think about this diagnosis now?
4. What did you do in order to learn more about the disability?
5. How is like being the mother of X? (name of the child:X)

   Is there any difference in your mothering between X and your other child?
6. How is your typical day with X?

   Did you experience any problems?

   What necessities being the mother of X?
7. How was your relationship with your husband before the diagnosis of X?
8. How can you describe your current relationship with your husband now?
9. What are your expectations regarding your child's future?
10. Which message would you like to give as a mother of children with special needs to mothers?
11. How did your child's disability affect your life?

    Did the disability contribute to you positively?

Procedure

Before conducting this research study, with the purpose of fulfilling the ethical standards for human research, the permission from "Institutional Review Board for Research with Human Subjects" (the Turkish of this board INAREK) in Boğaziçi University was taken (See Appendix F for INAREK permission form).

Before the interview, each participant was given information orally about the purpose of the study. Then a consent form was given to participants. When they accepted to sign the consent form, voluntary interview session started. The purpose of the study and their rights as a participant was mentioned in consent form in detail (See Appendix C and D for Consent form in English and Turkish).

In order to collect data, permission to use audio recording in interview sessions were taken. If the participants did not allow use audio recording, all things the participants tell during interview would be written in verbatim. But all participants approved the use audio recording so that there was no need to take notes. Data were collected in Turkish. Each mother was interviewed once and each session took at least 30 minutes. However, some of the interviews lasted more than an hour. The longest interview lasted an hour and twenty minutes. After data collection, information building was conducted in order to provide mothers information about their right as parents of children with special needs. Another aim for information building session was to make mothers leave in positive feelings. It was also beneficial because after telling their stories, mothers were informed about some important issues of parenting a child with disability and gaining awareness about their legal rights.

Pilot Study

After the interview questions were formed, a pilot study was conducted. With this pilot study, it aimed to understand the clarity of questions and correct the statements in an appropriate way to prevent any confusion or missing information on behalf of the participants.

Pilot study was conducted with one participant. This participant was a 33-year-old housewife. She graduated from primary school and she was from middle SES. This participant had a 10-year-old son having mild intellectual disability and he was also diagnosed with speech disorder. The participant gave permission to use audio recording so that it was easy to follow the whole interview.

After the pilot study, it was seen that questions were not asked in the format that made mothers talk deeply about their stories. The interview took only 15 minutes. The participant found questions too broad so she could not bring the important pieces of her story together. Because of this reason, subquestions which were predetermined before were asked to the participant. Specification of questions helped the mother focus on her story in detail. Moreover, in the last question, she could not understand what we refer by “her family”. New sub-questions were added to the interview questions in order to help participants remember different points of their stories so that they could start new topics in interview.

Data Analysis

Thematic approach was used in this research study because this approach is used to identify, analyze and dividing patterns within data (Braun & Clarke, 2006). Thematic approach was appropriate for not only describing and organizing data in detail but also interpreting different aspects of research topic (Braun & Clarke, 2006).

Constant-comparative method was used in this study. Constant-comparative method is analyzing similarities and differences by making systematic comparisons across units of data (Ryan & Bernard, 2003). The constant comparative method includes breaking down the data into separate units and coding them into categories (Glaser & Strauss, 1967). According to Taylor and Bogdan (1984), “in the constant comparative method the researcher simultaneously codes and analyses data in order to develop concepts; by continually comparing specific incidents in the data, the researcher refines these concepts, identifies their properties, explores their relationships to one another, and integrates them into a coherent explanatory model" (p. 126).

Identity of the Researcher

During my three-year career in counseling at a public primary school, I have been working with students with different disabilities in inclusive practices and mothers who have children with disabilities. When I work with mothers of children with disability, it is very difficult to understand their lives because their experiences are unique and vary according to different needs of their children. As a counselor, I hesitated to counsel them due to lack of knowledge in this special problem area.

After studying and investigating disability and mothers' experiences, I prepared a support group which was designed to help mothers whose children have disabilities in our school. By this group sessions, it was aimed to make members have awareness about their process of having a child with disability, make mothers use the coping mechanism of other members whose children also have disability and have the same experiences, give some information and abilities about parenting. Also sessions were designed to provide mothers some skills to fulfill the educational and developmental needs of their children. It also provided support for daily stress mothers of children with disabilities experienced. In these seven group sessions, they welcomed me to their world and shared their experiences, problems, stressors in their lives with the group (See Appendix H for mother support group sessions). While the sessions were going on, I realized that there are not enough studies which focus on experiences of mothers of children with disability. Then, I decided to work on this topic and make these mothers' unique experiences and common problems visible.

CHAPTER IV

FINDINGS

In this chapter, findings derived from data analysis were presented. After the data analysis, 11 themes emerged. These themes are pregnancy, diagnosis process, current feelings about diagnosis, getting information about the disability, perception of being mother of a child with intellectual disability, living with a child with intellectual disability, relationship with their husband before diagnosis, current relationship with their husband after diagnosis, expectation from the future regarding their children, messages to mothers and influences of a child with intellectual disability (Appendix J). Major themes were identified and were discussed below respectively.

The data were collected in Turkish, and then they were translated into English by the researcher. Participants' statements were quoted under the relevant themes. Participants' original statements were given in Appendix G (After the name of the participants in quotas, there was a letter "G" and a number. In parenthesis, "G" refers the Appendix G, the number next to G refers the order of the quotas in Turkish form in order to make reader follow the Turkish and English form of quotas easily). In order to introduce participants, crucial details about participants were given but with the aim of increasing confidentiality, each participant and their children were provided with a pseudo name in Turkish.

Themes

Theme 1: Pregnancy

In this theme, mothers were asked about their pregnancy. This theme, pregnancy, enabled researcher to understand how mothers experienced their pregnancy. In this theme, mothers discussed at three different sub-themes under the theme of pregnancy:

First Impression

In this sub-theme, mothers talked about how their pregnancy was. When the mothers were asked generally how they remembered their pregnancy, only 2 mothers defined it as problematic and 7 mothers interpreted this period as “relaxing”. One of these two mothers who was living with her sister-in-law talked about her marital problems and stressful situations during her pregnancy and how these situations reflected on her baby’s health:

> My pregnancy went so horrible. We had many marital problems. I had no problems until my sister came to our house with my husband as a surprise for me. I did not know her coming and my sister-in-law did not want her. Because we did not take her permission, we experienced many problems. When my sister came, I was taken to the emergency clinic. My baby had pain in my womb. Bleeding started. We went to hospital directly. They took my son’s cardiac rhythm under control. My son’s cardiac rhythm was deteriorated because of the stress I experienced and he had pain. (Hediye, G.1)

The other mother remembered her continuing nausea for three months and her worries about the possibility of unborn baby’s having epileptic attacks like her first child:

> I was 24 years old. The first three months of pregnancy started with nausea and I was disgusted with everything. I gave birth at the seventh month of gestation. Water broke 12 hours earlier than delivery. I gave an early birth but it was not C-section. My first daughter had epilepsy. When she got epileptic seizure, she turned purple and clenched her hands. I had worries about my second daughter also experienced that attacks. (Mine, G.2)

The rest of the mothers remembered their pregnancy as relaxed and comfortable. They became happy when they remembered that period. Hande enjoyed remembering her pregnancy memories:

> I got married and after a month, I got pregnant. It passed great, it was so nice. My demands were fulfilled and I wanted everything; my husband did whatever I wanted. I was eating plum abundantly. Yet, our friends were making fun of me and they told that plum tree would come out of me. There was no other problem. I was frequently having my pregnancy check-ups done regularly. Everything was going normal. There was no problem that made me upset. (Hande, G.3)

On the other hand, while interviews were becoming deeper and mothers were talking about the details of their pregnancy period, only two mothers out of seven did not mention any problems. They have just talked about how they learned that they were pregnant. For example, Aylin only explained how she found out that she was pregnant:

> I was 40 years old and I got just retired. I found out my pregnancy after 2 months passed by my retirement. First I did not pay attention because I assumed that I entered menopause. I did not see a physician. After two months, I went to hospital and the physician told me that I was pregnant. I got surprised and shocked. I said what is happening to me God. (Aylin, G.4)

But 5 mothers talked about different problems such as job stress, preterm labor and physical problems of their offsprings after they expressed their gratitude regarding pregnancy period.

Melike experienced job stress and pressure to get the work done as with due date. Because she continued her job until her 8th month of pregnancy, she felt more stress and pressure on herself at work day by day:

> My pregnancy was not difficult in contrast with my first pregnancy. The first four months, I did not eat well because of excessive nausea. Then my eating habits turned normal routine. I did not experience any problem but I had a very tough work. I relate my daughter's disability to that job. I was working time-limited job in a car factory. I was making air bags. They made pressure on me. Because I worked fast, after I finished my job, I helped others' staff. I forced myself and they did not care that I was pregnant. You can do it, do it! They saddled me with many tasks. (Melike, G.5)

Selma waited for two days after her water broke in order to deliver normally. Because there was no water, she had C-section. The other three mothers explained different physical complications in their babies. For example, Neriman said that "virus" was found in her triple test during pregnancy ("Triple Test" is performed in the second trimester of pregnancy to screen any chromosomal abnormalities in unborn baby). Her baby was delivered in C-section in 36th weeks in order not to put baby at risk.

Filiz mentioned how the doctors diagnosed her son's cyst in his brain and hydrocephaly in the fifth month of her pregnancy. And Necla was told her baby's water bubbles formation in the fourth month of pregnancy and how she was scared when the doctors said that there was a possibility of having a baby with disabilities if the bubbles would not disappear.

During interviews, when I asked participants what they remembered about their pregnancy they generally seemed happy and tried to go back those years. Although many of the mothers experienced problematic events during their pregnancy, they always attached positive feelings to this period. They experienced this period positively. Necla started crying when I said her daughter's name and pregnancy. It is more interesting that this mother said that there was no important and crucial memory about her pregnancy. Then she added water bubble formation in her baby's brain. Her face and mimics looked sad but she said that her pregnancy went smoothly. Other mothers also mentioned different problems during their pregnancy but not at the beginning. In my opinion, it might result from denial of negative events during pregnancy about their babies. It seems that they may want to remember their pregnancy positively.

Expectations

In this sub-theme, mothers discussed their expectations about their babies. While talking about memories of pregnancy, mothers were asked about their expectancies regarding their unborn babies were. Seven mothers expressed but 2 mothers did not mention any expectations. Four mothers out of seven told that they had no special expectations and they told that they had expectations as other normal parents had. When they were asked what "normal expectations" of parents from their babies, they defined it as having a typically developing child as his or her peers, being healthy, growing up and going to school. But in this respect, these mothers did not show any explicit expectations but they had expectancies about having a "typical baby" implicitly. Selma remembered her expectancies:

> He was our first baby but we did not have very big and important expectations in contrast to other parents. I wished him to grow up as his peers, he would determine his way and do whatever he wants. This is it but we experienced such a kind of surprises. (Selma, G.6)

Different from Selma, 3 mothers explained their expectancies in a more detailed way. Neriman told that she just wanted her offspring to make her a typical mother. Aylin said that her baby would be the only son in the family and they had different expectations from a boy. Lastly, Mine told that she had nice expectations from her second baby like:

> Of course I had positive expectations. At least, I wish they would go to school. I was not a student who likes going to school. If I liked school, there would be no obstacle to discontinue my education. Some parents did not want their children to continue their education. I did not have this kind of problem. But I dropped out school voluntarily. It may be childish. But if I had a chance now, I would have dignitary. Because I was not able to understand it, I wanted to explain it to my daughters and wanted them to have pleasant future…I said that my first daughter was hospitalized but we were not aware of her. But our second baby was planned. I expected to experience things what I could not do with my first child. But my second baby was worse than the first one… I wish at least my second daughter to be healthy. (Mine, G.7)

Mothering

In this sub-theme, mothers were asked what kind of mothering role they expected to have. After expectancies about their babies were asked, the next one was their expectancies of their mothering role before the delivery. Five mothers of out nine did not consider any mothering role in their pregnancies. For instance, Aylin said "We did not have any plan or project. I was just pregnant." (G.8)

Other 4 mothers told that they thought about their mothering role. Neriman defined her mothering role as being only mum who was breastfeeding, playing with her baby, waiting at home for his son's coming from school and being a relaxed mother. Selma thought that she would not have any problem as a mother because of her calm and good natured. Necla assumed that she would be a good mother who was well-disciplined and altruist. On the other hand, Mine told that she had expectations about how a mother she should not be:

> I did not expect my mothering role like this. I became a very patient and self-giving mother. I have changed so much. I was so light-headed and I did not look back. For instance, I used to drive car too fast and I did not care. But now I think twice because I have two daughters sitting at the back of the car. In other words, I was not like me. I learned to live not on my own. My priority became my children and my family. I changed incredibly. (Mine, G.9)

When analyzing the mothers who defined their expected mothering role during their pregnancy, it is understood that they have all experienced disappointment about their mothering role when their children started to grow up. Because in my opinion, there is a discrepancy between their expectations of mothering role and the reality, they started to change according to the needs of their children. For instance, although they stated that they planned to be well-disciplined mother during pregnancy period, disability and health condition of their children changed their plans and expectations. They have just wanted to be a typical mother as Neriman expressed:

> I was a mother who is hunger for a baby. I fulfill his all needs because I raised an unhealthy child. "Did I become a mother?" will be the name of my prospective book that I will write. I did not become a mother. I became a caretaker, a doctor, a nurse and I always fall all over him. I have never kissed him to my heart's content. I have never become angry and hit him. I have never been relax and comfortable as other mothers. I really want to be. I wish to wait my son at home now, not at school. But I experienced this. (Neriman, G.10)

Theme 2: Diagnosis Process

In this theme, mothers discussed about their children's diagnostic process and their getting medical and educational identification report processes. This theme consisted of three sub-themes named as perception of differences in their children with regard to children's mental situation, first reaction to the diagnosis and knowledge about diagnosis.

Perception of differences in their children

In this sub-theme mothers expressed how they recognize differences in their children, so this sub-theme enabled researcher to understand mothers' perception of differences in their children with intellectual disability. When mothers were asked how they understood the difference in their children, they shared their stories in three sub-categories as health problems, recognizing difference in their children and getting report process.

When mothers were asked when and how they recognized differences in their children, firstly all mothers talked about medical problems before or after birth. Because all children were ill from their early ages of life or birth on, mothers started their "difference stories" from the life-threatening conditions of their children. Four mothers' experienced health problems during pregnancy (prenatal), 2 mothers during birth (perinatal) and 3 mothers after birth (postnatal). For example, Hediye talked about what she and her baby experienced in pregnancy:

> Doğukan was turning in my womb oddly. He was so hyperactive as if there was a snake in my midsection. He was moving around my midsection. Because it was my first pregnancy, I could not understand…but after a week, our problems started. I was hospitalized in a state hospital. They administered preparate injection for a week. That injection was used to turn Doğukan's cardiac rhythms to the normal level. (Hediye, G.11)

Neriman learned that there was a "virus" in her triple test and she had to make a special diet for survival of her baby while Filiz was informed about the cyst and hydrocephalus formation in Mert in her five-month-old pregnancy. At her fourth month of pregnancy, Necla was experiencing a quiet different problem:

> I went to doctor at my fourth month of pregnancy. My gynecologist said that there was a water bubble formation in Betül's head. I was upset but my doctor told me that the bubbles were not important and could be disappeared and also, I cannot remember, but at a specific month of pregnancy it should be gone. He also added that in some pregnancies, water bubbles did not recover…After 2 months, I was examined and he told me that water bubbles disappeared But I felt regretful about this problem. I asked what would happen if bubbles were not disappeared and doctor said that my child could be disabled. It was always in my mind. (Necla, G.12)

In perinatal problems, two mothers, Mine and Selma, had problems about delivery. Mine gave birth at 7th month of her pregnancy. She had a premature labor. But in my opinion, she was also sharing a common fate with Selma. In their delivery, their water broke before the delivery. Mine's water broke 12 days earlier than delivery. But Selma waited for a longer time to delivery and expressed her worries like:

> I waited too long to make vaginal delivery in my son's birth. I waited for 2 days. My water finished during delivery. I suffered birth-related pains although my water finished 2 days earlier than delivery. Because vaginal delivery was not possible without water, I gave birth by c- section. Until the last period, everything went normal. But in delivery, I experienced this. At that, I supposed that my water broke early, Arda waited for a long time for vaginal delivery. I thought that his disability may come from my C-section delivery without water. (Selma, G.13)

These 6 mothers faced with physiological problems before they hugged her babies. Their babies started their lives with problems and challenges. On the other hand, 3 mothers gave birth and their problems arose as their babies were growing up. Aylin was the first mother who faced with intellectual disability after her delivery. Aylin said “after birth, doctor told my son has Down syndrome and he is Mongol. They suspected and told that they were not sure but suspected. We went to İstanbul University Medical School and learnt the truth. They told me that my son has Down syndrome and he is behind his peers and he will be always behind his peers in his later ages.” (G.14) Melike expressed how she was shocked when doctors told that her baby was dead:

> Burcu had a brain hemorrhage when she was 7-month-old. Doctors did not diagnose her first brain injury. Because I insisted that there was a problem in her brain, doctors started investigating but after a week she had the second brain hemorrhage and doctors gave her up for dead by saying she would die. Even, my husband tried to fight with one doctor… We had our daughter got brain surgery but doctors said that she would die or she would be disabled even if she managed to live… After brain surgery, we stayed at the hospital for 2 months. She got the second surgery. They placed shunt… when we were discharged from hospital; there was no progress in Burcu. Like vegetative state, she could not speak, hold her head and give response. I struggled with this for two years. (Melike, G.15)

Hande was also so afraid when she saw massive bleeding in her daughter Nazlı:

> Nazlı got a fever at that night. My mother-in-law told me to give aspirin for fever. I gave aspirin to my baby and she slept. When we got up in morning, our bed was drenched in blood. It was like fountain… Her nose was bleeding. We went to hospital… she was 3 years old. Doctors analyzed and said that there was no white cell left in her blood. Then they found blood from İstanbul University Medical School. She was hospitalized for a month. Her blood was changed. Also she had hypersplenism. Doctors warned me that I should protect her not to being hit or fall as a fragile glass… she was diagnosed as hemophilia (See Appendix I for further information about the disorder). (Hande, G.16)

Some children had physiological problems before or during birth. But their new health problems came up as they grew up. For instance, Neriman’s son, Ahmet, who had “virus” in his triple test and premature labor, was diagnosed with maple syrup urine disease which is a metabolic disorder. Neriman expressed how her first feast of sacrifice with her 11-day-old baby turned into a catastrophe:

> It was my first and real feast. I gave vitamin to Ahmet. His color changed and turned to purple. I guessed that I was seeing purple because of fluorescent lighting. He got purple suddenly. My husband and my father came from mosque and asked me why his color was purple. At that moment, his face was deep purple and his head fell down. We supposed that he was dead and we screamed… we went to hospital and they told us that we were losing our baby… doctors gave a false diagnosis. Even today doctors do not know this disorder…From urine analyzing; it was diagnosed as metabolic disorder which was understood from the smell of urine. It said that this disorder could not be diagnosed during pregnancy. (Neriman, G.17)

Filiz’s son Mert who had hydrocephalus formation (See Appendix I for further information about the disorder) in his brain during pregnancy underwent brain surgery in which he was placed a shunt 2 months after his birth. Selma’s son Arda had reflux until he was 3 years old and he was excessively vomiting. Necla’s daughter Betül was understood to have cardiac problems 40 days after the birth. Then she had a heart surgery. Like Necla, Aylin was also dealing with a son who had a congenital heart defect known as hole in the heart but that was not the only problem he had:

> After he was born, doctors said that there was a hole in his heart and he had Down syndrome. We went to hospital and stayed there for 3 months for pneumonia treatment. Because his illness was not recovered, they sent us to American hospital for better care. There he had a cardiac surgery. (Aylin, G.18)

While Aylin and Necla struggled with cardiac problem of their babies, Mine realized some attacks in Canan’s arm and rushed Canan to hospital:

> One day I saw involuntary, unexpected movements in Canan’s arm and we rushed her to hospital. Doctor explained that she had a seizure and she was diagnosed with “Fahr Syndrome” at the age of 1. After that, we ordered a special injection from Germany. With this injection, doctors tried to stop her seizures. She had small seizures 60-70 times in a day. She was administered a long treatment. Then she used some medications. But her seizures were very

> hard. She was taken diazepam and she was lack of oxygen. Because his brain experienced lack of oxygen, we had to hospitalize for long hours. (Mine, G.19) (See Appendix I for further information about the disorder)

Lastly Hediye was afraid because Doğukan did not cry just after the birth:

> After birth, Doğukan did not cry. I realized it, can you believe me? They were suturing me while doctor were hitting hips of Doğukan but he didn't cry. I asked the doctor why he did not cry. He told me that he was suturing me why I did not mind my business. He told that he was a baby he may not cry… because I was depressed, I did not eat for two days before delivery… because I had low immunity, the baby ingested his stools during delivery, so he could not cry after birth. With the aim of cleaning his lungs, he was put in incubator. (Hediye, G.20)

After children started growing up and their health problems becoming somewhat recovered, mothers were catching some differences in their children. Two mothers understood differences from behavior problems of their children whereas other six mothers realized differences from their children reaching developmental milestones later than their peers. Necla and Hediye started observing their children and they saw some prominent behaviors different than other children. Necla told how she saw some behavioral differences in her daughter:

> …We focused on Betül at the time of her cardiac surgery, we all dwelled on her health problems. But she was neither hyperactive nor happy child. We always attributed her behaviors to her heart problems. For instance, Betül was so irritable child. She has even bad temper now. For example, she always beats other children for no reason… Betül was so aggressive. For instance, she pulled other people's hair for nothing… she had behavioral problems. She did not have a good dialogue with other people. She got along well with us but not with her peers. I started comparing her with other children. I realized that she did not act as a normal child because she fought with other children vainly. Of course children can fight but Betül was acrimonious for no reason. (Necla, G.21)

Hediye exemplified the same problems by telling her observations about her son Doğukan:

> When he was three years old, his excessive hyperactivity attracted my attention. How can I describe it, when I took him on my lap, he ran off like a snake. It was unbelievable. He even did it at the age of 1.5. When he was 3 years old, he hit his head to the floor at the time of his range. He moved too

> fast and messed up the table… At kindergarten, his teacher also realized it. He had difficulty in having relationship with other children. He had even that problem at the age of 3 because when we went into a place where children existed, he did not hurt them but he played in a maladjusted way and he spoke with other children by pushing them. Doğukan always did it. (Hediye, G.22)

These mothers realized difference in the behaviors of their children because their children were diagnosed with not only intellectual disability but also ADHD. They saw the symptoms of ADHD because their children did not have problem about reaching milestones as their peers. On the other hand, other mothers highlighted the backwardness in their children. The differences she encountered were indicated from Mine as follows:

> All abilities developed late in Canan. She started walking when she was 5 years old. Likewise, she learned talking about the age of 5. She even cannot care herself now. Her toilet and bathing rituals are done by me. Also her tying her hair up, putting on her clothes, tieing her shoelace... (Mine, G.23)

Hande remembered how she realized the differences in her daughter as follows:

> When she started school, her comprehension was slow. She could make addition but she hesitated what she did and whether they were true or not. She brought it to me and I confirmed them. Her teacher told me to send Nazlı to special education center for individual rehabilitation support. When I discussed the issue with my mother-in law, she got angry with me about the possibility of Nazlı's being idiot. It's very well but Nazlı was not like other normal children. When attending to be normal, she was playing with 3 or 4 year-old-children… In her infancy, she spoke well and could say "mum and dad". She started talking early but she could not make sentences…(Hande, G.24)

Analysis of data revealed that all mother realized that their children had difficulty in reaching developmental milestones which differed them from their peers. Table 5 shows problems existing in milestones of the children in this study.

Table 5: Problems Existing in Milestones

Milestone	Aylin	Selma	Hande	Melike	Neriman	Filiz	Necla	Mine	Hediye
Walking	√	X	X	√	X	X	X	X	√
Talking	X	X	X	√	X	X	√	X	√
Self-care	X	X	√	X	X	X	√	X	X
Toilet	X	X	√	√	√	X	√	X	√
Language	X	X	X	√	X	X	√	X	√

(√ refers their children did not have problem in reaching that developmental milestone, X refers their children had problems or delays having that milestone)

Apart from mothers above, Selma realized delays in reaching milestones of his son as well as mentioning his behavioral problems as follows:

> After age of 3, his walking, talking delayed compared with his peers. When we compare Arda to other children, his progress continued in different ways. For instance, he did not cry when he got up. He did not cry and he was always happy. He always preferred to sleep in dark places. He could not sleep in lightened room. He is still like this. He woke up with very low noise. He is a light sleeper. He was so sensitive… He was swinging when he was a child…In addition to these, Arda was so sentimental. He got affected with a melody. While my nephew Ömer was beating time with music, Arda closed his ears and cried. We turned off the music because he did not like it. His walking, playing with different tools… Ömer could do these but Arda got bored, did not want to do and his attention got lost… In kindergarten, he could not play with his friends… his painting was different from his friends' ones. He was scribbling. He could not paint within boundaries. He did not join the play. He could not memorize a poem. He could not learn songs or beat time. (Selma, G.25)

After mothers realized the differences and asked themselves what was wrong with their children's development, most children started school and it was the beginning of medical report process. In school age, the situation and differences of their children became apparent. Six mothers struggled to get the medical and educational report for their children. The difficulties they faced even before the beginning of school and getting report were depicted by one of the mothers as follows:

> I realized the problem from his age of 3 but I could not explain it. They did not believe me and told that he was a boy and these behaviors would change.

> I had a struggle until second grade… our kindergarten teacher got an appointment from a doctor but my husband and my sister-in-law did not accept it. When Doğukan started school, we experienced more problems. But before this, in kindergarten we went to department of psychiatry. But the doctor did not diagnose the problem. She said that he may be diagnosed with hyperactivity but he was so young and his hyperactivity was normal. I told the doctor that I realized something was wrong but I could not name it… My husband neither took Doğukan to hospital nor allowed me to send him until we had trouble with Doğukan's first grade teacher. (Hediye, G.26)

Because the husband of Hediye did not accept the situation and did not allow his wife to refer his son to doctor, teacher did not accept Doğukan to her classroom and they tried three schools. Then Hediye found a teacher and told their story:

> … I told my story and I saw that the teacher was crying. She told me that she would accept Doğukan to her classroom but I had to take him to doctor and persuade my husband. I told that there was no need to persuade my husband because I would take my son to doctor on by own. Then I took Doğukan to İstanbul University medical school for three days secretly. I kept the situation as secret from my husband. I even did not know how to go to Çapa by myself. Doğukan did not behave himself. I talked to doctor. Normally they would give the report after 3 months but the doctor prepared the report after 15 days when I told my life… I took the report and I went from center to center for special education in Kartal, a district in İstanbul. I arranged the rehabilitation center and his special education teacher. Then I called my husband and told whether he wanted to get divorced, he could go to courthouse before coming home because I took the report. Then with my pressure, Doğukan was eligible for receiving special education services. (Hediye, G.27)

Melike encountered the same difficulties because her daughter also was rejected from classroom by her teacher and she did not know how to get the report and get started special education. Likewise, Filiz tried to get diagnosis for his son in his third grade. She could not persuade the teachers that his son was different and needed report for special education. Whereas, Necla could not persuade the doctors that her daughter had prominent differences and she had to get a diagnosis. She took the medical report after she sent her daughter to hospital twice at the age of 5.5. Hande and Selma had the same problem because their husbands also did not want to get report because they did not think that their children had a problem. Selma expressed her opinions as to getting report as follows:

> Before first grade, Arda went to kindergarten twice. They referred us to Guidance and Research Center. I could not understand what was going on at that time. That center referred us to different centers. Then this hospital sent us to different place. I cannot even understand the system now because in Turkey, there was no system about getting diagnosis and report, taking education in the line of diagnosis, awareness-raising of parents. I am still questioning how I can educate my child, whether the diagnosis my child got is true and his special education is related to his diagnosis or not. But there is a system and I have to follow it. If I rejected this system, I should stay at home with my child. I do not have any other option. In this issue, everything is limited… (Selma, G.28)

While these 6 mothers were coming through a long and difficult process for report, 3 mothers did not have difficulty to get report because their children got their diagnosis in their infancy period. For instance, Neriman took the report for his son at the age of 2.5; Mine took it at the age of 2 and Aylin did it when his son was 1.5 years old. Because their children got report before the school age, they received special education support early on.

To conclude, mothers experienced distressing situations starting with health problems, continuing with realizing the difference and then running after the doctor to learn what happened to their children. In this process, they seemed to be tired physiologically and psychologically. Because of this reason, next step, first reaction to diagnosis may be well understood by looking at the issue by taking this process into consideration.

First Reaction to Diagnosis

In this sub-theme, mothers were asked how they reacted when they learned the diagnosis of their children. With this sub-theme, researcher understood first reaction of mothers against disability. It is seen that mothers' first reactions were parallel to the research study results in literature. They were in shock, denial, suffering or depression (Sen & Yurtsever, 2007).

All mothers in this research experienced shocked when they learned that their children were diagnosed with intellectual disability. They were overwhelming with grief as Aylin stated “I swear, I cried a lot. I did not know what Down syndrome meant. I asked my doctor. I did not know the words Down syndrome or Mongolian.” (G.29)

After shock stage, their stages differed. Five mothers were in denial, 2 mothers in suffering and other 2 mothers were in depression stage as their primary reactions.

In denial stages mothers refused to accept their children’s diagnosis. These mothers used denial mechanisms in different ways. For example Neriman found a new explanation for his son’s diagnosis of mild intellectual disability:

> I said different but it is Ahmet’s report. I mean enzyme deficiency, feeding problem, not mental problem actually. Because of that disorder, therefore he reached milestones later than his peers, they cannot explain the situation…I caught the last part of disorder, feeding problem. I do not accept the others. There is nothing like this. God does not do it! He gave him so special to us because we wanted him very much. That is to say, he does not have a problem; he is just a patient with feeding problem. I just accept it. You can realize from my talking, I look at the problem from this side. If I did not do it, I could not stand it. My strength will be over and I can’t do anything for my son’s benefit. (Neriman, G.30)

Hande was so sad to hear that her daughter had mild intellectual disability but she was helped to see the glass half full, not the deficiency. Hande said “I was so sad. But the aunt told me not to worry because Nazlı was so smart. At least she can take care of herself; she does not have a problem.” (G.31)

Selma had the similar reaction with Hande. She also thought that his son was smarter than what the diagnosis said:

> I was expecting a deficiency but not like this. I was expecting diagnosis as learning difficulty, not intellectual disability. I did not think of mental

> disability because Arda has a good visual memory. He does not forget what he sees. You can go to anywhere you go before with the help of Arda. He does not forget the directions. He can remember something that you did years ago and he tells you back. That's why mental disability does not suit my son. But as I said if this diagnosis was taken, I thought what should be done for Arda." (Selma, G.32)

It seemed to be that because she did not know what Down syndrome meant, Aylin also made an assumption to heal this disability:

> Doctors said that my son has Down syndrome, he would follow his peers behind. They told me that he could learn something with education. We could not understand the situation at that time. I supposed that I could get over this disability by education. Then we started struggle. (Aylin, G.33)

Filiz was another mother who got sad with the diagnosis of her son but she claimed that she was not very sad because she voluntarily got the medical report for her son although no one referred her to the hospital. On the other hand, she waited for two years to get the report although she was aware of disability and her son is coming always behind his peers at school.

While mothers above experienced denial as a result of diagnosis of mild intellectual disability of their children, 2 mothers, Melike and Necla, felt suffering because both of them had a long and difficult process of having medical reports for their children. While fighting with legal process and diagnosis, they felt grief. For instance, Necla started looking for a solution for the unknown situation of her daughter from the age of 3.5. Even while she was talking how to get report for her daughter's disability, she cried and the grief she experienced was still visible.

Like Necla, Melike also had difficulty in getting report. Melike stated:

> In 1st grade, I just warned her teacher that Burcu should not be hit by head. I said my child does not have a problem, I did not know mental problem yet… the teacher said "I do not want her, send her to handicapped school." I cried for ten days outside the classroom… I cried a lot because the teacher did not want my child… I applied to rehabilitation center. They told me to get medical report and then they would start special education program… I tried

> for getting medical report but because my husband did not have social insurance for two months due to his new job, we did not get the report… At those 2 months, I fought against the situation of Burcu. For a year, I did not do housework; we were eating at my mum's home. I taught Burcu how to read and write… when getting the report, I got upset and cried. It is not easy. At that time I did not know what mental disability was. I did not know anything. This was the first time I faced with mental disability, how could I know? (Melike, G.34)

Life of Melike and Necla was having hard times before they got the medical report and at this process they suffered, cried and fought with the situations and protocols. But for Hediye and Mine, learning the diagnosis created more problems later on. Hediye remembered how she worried about what to do with that diagnosis:

> Hyperactivity attention deficit was written on the report. I learned more or less what it means. However, I felt sad because it was like a last drop. It was stated that my son should go to hospital and he has mild mental disability. I started worrying about how we would go to hospital continuously. I could feel sad for Doğukan. I told how I can go to hospital again because it requires persistence. I thought how I could explain the situation to my husband. I was just thinking of it. Of course I was sorry for Doğukan, sorry about why my child was in this situation. (Hediye, G.35)

Hediye experienced worries because feeling not enough strength to fulfill the special needs of children triggered depressionhood as literature mentioned (Sen & Yurtsever, 2007). Mine was also experiencing major depression and said "when I learned, I psychologically fell down. I had a fear of losing my child." (G.36)

Although both mothers were shocked and sad for the diagnosis of their children, they used different thinking mechanisms and went through different stages. Some were in denial to protect herself as Neriman did, some were depressed because of the responsibility and fear of what how their husband would react as in the case of Hediye, some were exhausted while trying to get medical report and diagnoses as well in the case of Melike.

Knowledge about Disability

In this sub-theme, mothers were asked whether they had a prior knowledge about their children disability. Eight mothers told that they did not know anything about mild intellectual disability before, and only one mother said that she knew about the disability condition before the diagnosis of her daughter. When mothers learned the diagnosis of their children, they generally tried to understand what intellectual disability meant. Hediye told her confusion against what was written in the report of her son:

> I learned what mental means from our special education teacher. I heard about hyperactivity from TV. It comes with restless, hyperactivity and behavior problems, attention deficit, I knew it. But I could not understand mental retardation. I got the report and I asked to the teacher. I wanted him to explain it. Intellectually, he said, he was in a mild level. Doğukan is 7 years old but he acts like 6 years old or 5.5. He explained it in this way. I got sorry for it. I could not understand the report first but when I learned, I got upset because intelligence is very important. I also know that it will not be fixed. (Hediye, G.37)

Because they did not know what intellectual or mental disability, as written in medical report, means, they were confused and did not know what would happen to their children. But only Necla knew intellectual disability "I was searching on internet… I was looking for the tests Betül took from internet. Then I learned it." (G.38)

In my opinion, it shows why facing with an intellectual disability creates disaster in lives of mothers because most of mothers do not know what kind of problem they will deal with. Consequently, they could not use their coping mechanisms without knowing the aspects of disability.

Theme 3: Current Feelings about Diagnosis

In this theme, mothers were asked how they thought about the diagnosis of their children now. Five mothers were seen closer to acceptance stage while 4 mothers still did not accept the situation of their children. Mothers coming to acceptance stage were more relaxed compared to their first time of their getting diagnosis. Nevertheless, they were still having problems and crisis in daily life. Aylin exemplified this issue by stating:

> I am so happy with Utku. If Utku does not exist, I may forget smiling because I lost my loved ones. Now, my son is my friend and all I have… Now I overcame lots of problems. I was reading books about this. I overcame with Utku. However, we experienced some problems. For instance, while we were going to my sister's house, families at that apartment attacked at Utku. He was playing with children in that apartment. When children made a mistake, they were asked who did it. Children accused Utku. And Utku cannot defend himself. It is not nice. When I asked Utku whether he did it or not, he said that he did not do it. I knew because when he did, he always told that he did it. (Aylin, G.39)

Another mother explained the relief she experienced as follows:

> I am more comfortable now, I got relaxed. I am better than the past. Also, Betül is better now, she is different than the past. I felt relieved when she started learning something. When I realized that she could lead her life on by own, I calmed down. Now I feel good. (Necla, G.40)

Melike reflected her relief and how she accepted the situation of her daughter as follows:

> In these eight years, I scrambled with Burcu and she became better day by day. She was getting certificate of achievement until the fifth grade. She was successful in class. Her special education teacher was very good. After she left the rehabilitation center, Burcu started to slow down with her progress. Burcu was correcting the mistakes on the board at class and her teacher appreciated Burcu for her progress. But after the lessons becoming more difficult, her progress was falling down gradually. Now I did not interfere in her homework. She is doing her homework rightly or wrongly in her way. If they were wrong, her teacher would warn her. (Melike, G.41)

Mine was expressing her feelings about how she accepted her children's disability as follows:

> You did not do it or anyone else did not do it… I got accustomed to live with them and I praised to have these children. I could not breathe without my daughters; I am begging God not to lose them. Now normal children look abnormal to me… My life was identified with them. I never found the situation strange. It may result from my sister who has also disability. It was not hard for me… But now the thing that affected me is their seizures. I did not take offence at their mental or physical disability. I also did not take offence at their seizures but I became desperate… apart from this, I am not troubled with why my children were like this. (Mine, G.42)

Like Mine, Hediye also accepted the diagnosis of her son because she was struggling with difficult problem:

> Now I cannot think of hyperactivity or mental disability. I overcame them. At the moment Doğukan was suffering from more compelling problem, infantile psychosis. I am preoccupied with this psychosis. I left other diagnosis at one side because they remained unimportant for me. Now Doğukan have crying episodes. For example, yesterday while we were going to rehabilitation center he started crying. But he was weeping inwardly, he did not cry like this even in his infancy. It is too much to overcome. Consequently, his hyperactivity or other diagnoses are just stuff and can be overcome. (Hediye, G.43)

While mothers above accepted the diagnosis and try to normalize their life, 4 mothers were away from acceptance but their responses had varied. For example, Hande was still sorry for the condition of her daughter. She was still questioning why her daughter was acting like a child while her peers were becoming young ladies. She could not accept the difference of her daughter. Like Hande, Selma was also questioning but not the situation of her, she was questioning the diagnosis of her son. She considered her son's problem as less problematic than the diagnosis stated. She reflected her opinions as:

> These children cannot express themselves. How they can get diagnosis in a session for 5 or 10 minutes. Is this diagnosis right or wrong? I am still thinking about it. We came to this point. He got education with his report and learned reading and writing. He was an inclusive student. He does not have maladjusted behaviors or harmful behavior in his class. For a year, I attended the class with Arda… I realized that other children have more hyperactive,

> disruptive behaviors. I told that Arda does not have hyperactivity. He might have learning difficulty. He may be diagnosed with learning disability but now he has 70% of intellectual disability level in his report. (Selma, G.44)

Other 2 mothers, Filiz and Neriman, had regrets about the disability of their children. For instance, Filiz said that "I wished to send him hospital earlier and we may start special education earlier". (G.45) On the other hand, Neriman felt more regretful and put the blame on herself, medical doctors and his husband. She explained her feelings as follows:

> I think nothing of diagnosis because our doctors could have made medical analysis at first. When I was going to doctor for in vitro fertilization, I mentioned about our cross-cousin marriage. I gave information about my thyroid… I told it because I had worries. I had thyroid problem, could I get in vitro fertilization? Because hormonal level was high in my body and you would be also given hormone. I would be loaded hormones. Will be any problem in my baby? Moreover, I always believe in God, I am feeling. We have cross-cousin marriage, I told my husband, maybe God loves us and he does not give a baby to us because of it. Why are you rebellious? There is no rule that everyone can have a baby. But he did not agree with me… They could have transferred embryo to our baby after analyzing carefully but they did not. Our kin marriage could be taken into consideration. When I was pregnant, I wanted my medical doctor to make amniocenteses test but my husband did not accept it. He cancelled my appointment and I am still angry with him… I had a tooth pulled when I was pregnant in my sixth month. I was sorry for it. Besides, my doctor gave permission and I had my hair dyed. I am questioning everything… (Neriman, G.46)

These mothers were in the anger stage because they were angry at herself, her husband or medical doctor not to protect their children to have disability. They were questioning but not accepting the reality yet.

Some mothers were in acceptance stage but this does not mean that they did not feel sorry for the disability of their children. All mothers in acceptance stage were crying when I asked them their feelings about the diagnosis of their children. In my opinion, it may cause from their remembering difficult period with their children and still continuing problems. Although they cried, they expressed their relief after diagnosis and the stages they passed.

Theme 4: Getting Information about the Disability

In line with the purpose of the study, mothers were asked how they got information about intellectual disability. Analysis of data revealed that all mothers, except Hande, got information at least from their medical doctor. Hande neither knew intellectual disability nor sought information about it not until the days of interview. But other mothers got information from doctors. Unfortunately all information getting from doctors were not accurate. It looked like that even some information was wrong or it was misunderstood by these mothers.

Mothers were given the information about the situation of their children. Aylin mentioned how the doctor explained about the disability as follows “He has Down syndrome and he will not catch up his peers. He will be behind his peers. For instance, a healthy child can learn quickly but this child can learn slowly.” (G.47) Filiz were given the same information and she told that “our doctor operating on Mert told that he would come from 2 or 3 years behind his peers.” (G.48) As Aylin and Filiz, Melike also got information which was ambiguous and vogue as “doctors explained the situation as attention deficit and forgetfulness”. (G.49)

But Neriman got totally wrong information about the disability of her son. She told what his doctor mentioned them as follows:

> Our doctor told that until we have any treatment or medication for this disease, it damages his brain and all organs, not only mental. It could cause cirrhosis, kidneys could die out. But if he followed his diet carefully and got education properly, he can catch up his peers after puberty. In other words, he can pass his peers because he is feeding with special diet… for instance, all parents do not make zinc or lead test done for their children. But because they made all tests for Ahmet, they stop which minerals are high and fortify minerals which are low in body… (Neriman, G.50)

Apart from getting information from doctors, 6 mothers also sought information from different sources. For instance, 3 mothers got information about intellectual disability from rehabilitation centers. Moreover, 3 mothers got information via internet. Mine explained how she got information about intellectual disability as stating:

> I did not apply to anywhere. I got in touch with teachers in this rehabilitation center and doctors at hospital. They mentioned about why this disability occurred and how I should accommodate my life to this disability. Then, I used our technological advances and sought information from internet, and I gained experience. I looked for these. Also I asked doctors, that's all. (Mine, G.51)

In these mothers, Aylin was the only mother who got information from every channel she could have reached. Her learning and getting information period was described by herself as follows:

> When I learned what Down syndrome meant, I gave importance to his education. I looked for whatever I found. I was going to Marmara hospital and I started getting education from senior students in university… Then I applied to İSÖM (İstanbul Handicapped Center, latter name is İSEM, İstanbul Disability Center). There, I still prayed to "Sezgin Bey", he gave us family education. He told that if our child stayed with healthy children, he could become socialized. He led us and gave a book to me. They transferred senior students to our home for special education… (Aylin, G.52)

To sum up, mothers of these children lacked of information about the disability of their children. In my opinion, they needed to get information about disability in different developmental stages of children because some mothers had information but these were not reflecting what would happen to their children in near future.

Theme 5: Perception of Being Mother of Child with Intellectual Disability

In this theme, mothers were asked how they could describe being the mother of child with intellectual disability. This theme aims at understanding the mothers' perception of their mothering and feeling about their mothering role. Analysis of data showed that 6 mothers expressed both positive and negative side of their mothering by putting emphasis on its positive sides. Moreover, one mother saw the glass half empty while other two mothers emphasized on only positive sides.

Filiz and Neriman described their mothering with full of happiness. Filiz reflected her feelings as:

> I think it is a great feeling of being mother of Mert…He holds dear me more than my other children. I also hold dear him. It may come from this. I always stand by him but I do not know whether I do the right thing. We do not have any problem. (Filiz, G.53)

Likewise, Neriman stated her feeling of being mother of Ahmet as follows:

> Being the mother of Ahmet is a very pleasant thing. If I was born again for thousand times, I would again want Ahmet. I do not prefer any other child. I did not want another baby. I could have made vitro fertilization again for having a sibling for Ahmet. But I did not want to give Ahmet's financial opportunities and my love to another child. I did not want to divide them. If I was born again, I would be the mother of Ahmet. I would really wish it. (Neriman, G.54)

Other 6 mothers described their mothering role as pleasing and started description of being mother of their children with "it is very pleasant feeling". In addition to this happiness, they added the heartbreaking and difficult part of their mothering. Even though they felt resentment, they emphasized their happiness of being mother of their children. Aylin explained her thoughts of being mother of Utku as follows:

> Being mother of Utku is very pleasant because there is no person who does not like Utku in this stage. But previous periods were different and difficult. When I go out, children say "it is mother of Utku" and they say hello. He meets anyone and talks with them. When he hears any music, he starts dancing. He cheered me up. However, that is the one side. Other side is that when I see his peers going to courses and doing other things, I feel sorry. I ask myself what will happen to him after I die. That's the upsetting side… It has both sweet and bitter sides. While he was growing up, he became stronger. Sometimes as a person, I get ill and he starts acting stubbornly. He tries to do whatever he wants. I do not want to reinforce his behaviors and I sacrifice myself. (Aylin, G.55)

Furthermore, Selma focused on the great feeling of being mother of Arda as well as mentioning the hardship of being mother of this kind of child:

> Being mother of Arda is very good thing…Everyone loves Arda… It was very hard times for me when Arda started school because you could not make other people accept him. Besides, because little children are relentless, they cannot think maturely. They suddenly tell something. I experienced difficulty. Then I met parents of classmates of Arda. When we kept in touch with them, I explained them the difficulties waiting us outside. Arda looks as a normal child because he does not have any physical difference. Because of this reason, other people expected behaviors what they expected from “normal children”. Sometimes he acted strangely and he shouted and gabbled. If we were outside or at dinner, everyone stared at us. Even they did not look, we felt as if they were staring at us due to strange behaviors of Arda. As I told, when I explained other parents to these difficulties, I realized that they had no idea about it… people act more tolerantly to children with physical disability but they are not aware of children without physical differences but having intellectual impairment… that made me relax and I got over this problem. There is no other problem with Arda. I am very happy with him. I do not have any burden on me but sometimes I consider that he has also some rights. He should also play in the park with his friends and he acts freely like other children. (Selma, G.56)

Mine was complaining from the same issue as in the case of Selma. She stated her opinions as follows:

> I am very happy of having this kind of a child. Canan is very emotional and merciful child. Moreover, she is so sensitive. She suddenly gets nervous and calms down quickly. I wish she was a healthy child and she would be model for everyone. She is so sentimental and when she gets close to anyone, she loves very much. I have respect for her love. It is not a thing that everyone can do. It makes me happy and proud… She can still be a model but there are less people to take Canan seriously. It is what makes me annoyed. I felt resentment when I saw that some people look down on her and ignore her. If only they knew that they could lose their health all at once. Unfortunately, no one has this conscious. Because of this reason, she cannot be a model. Other people do not love immaculately as Canan does. (Mine, G.57)

These mothers mentioned above emphasized how they took their mothering role seriously and happy to be the mother of children with disability despite its difficult responsibility and distressing parts. They put heavy emphasis on their acceptance of this role. As Melike stated “It was very hard at the beginning… She could not accomplish something. Now we have trouble due to puberty but I am not complaining.” (G.58)

Apart from these mothers, Necla was exhausted from being the mother of Betül and she cries as follows:

> It is very hard… It is difficult from every aspect… She was a difficult baby. She is still forcing me due to her health problems and she has a disability… Her cardiac problem still continues. Also, she is very difficult child in respect to school and education. (Necla, G.59)

To summarize, they were happy to be mother of child with intellectual disability. But this does not mean that they are struggling. In my opinion, they were experiencing problems and in this struggle, they might have identified themselves with their children. Because they had a different mothering role, they might fling themselves into this role and it might have increased their happiness and importance of this role. They had heartbreaks and desires but they may have tried to get happy from the positive sides of their children.

Perception of Mothering of Child without Disability

In line with the purposes of the research study, it aimed to understand how intellectual disability affected the perception of participants' mothering role. Consequently, in this sub-theme, mothers were asked whether they saw any difference between their mothering of the child without disability. Because 8 mothers had at least one child without disability, they compared their own mothering role. But Neriman did not have any other child and Mine did not have child without disability, so they compared their mothering role with other mothers of children without disability.

Only Aylin did not see any difference between mothering to Utku and her daughter Seyhan. She told that there was no difference and they were both happy.

Aylin mentioned about the sameness of her mothering whereas other 8 mothers put heavy emphasis on difference of being mother of a child with disability and one without disability. But they came up with different points all of which reflected their own feeling about mothering.

Two mothers, Filiz and Hande, stated that their mothering to their child with intellectual disability was different from their other children with respect to its privileges their children with disability had. Filiz stated that "I try to guard Mert more than my other sons. I am aware of it and others also know it… I feel as if he would be hurt. It may not happen but it is a maternal instinct." (G.60)

While Filiz was overprotective mother for Mert, Hande was taking care of Nazlı as a baby and showed affection. Hande told that "I have another daughter too but the love of Nazlı is different for us… She comes and sits beside me. Then I play with her like a baby and love her. " (G.61)

Moreover, Melike expressed how she was regretful due to the differences of her mothering toward Burcu and her other child. She mentioned her feelings and how she tried to find the balance in her mothering toward her children as follows:

> At the beginning, I excluded my oldest daughter and I focused on Burcu. Even I punished my oldest daughter. Now, I am begging and apologizing for these behaviors and I wondered how I could do these. Even sometimes I am crying for my behaviors at past… Now I do not show favor and do not discriminate them. Now I am conscious. (Melike, G.62)

Selma also had problems with her other son after he realized the any difference between himself and his brother. Selma cried and mentioned her sadness as a mother:

> My other son, Asaf, is very successful child. Although he does not go to school yet, he starts reading on by own. I could not explain to him that his brother has different characteristics… He asked why his brother was acting like this, why he got crazy and made home messy… For instance, we were doing homework with his brother from the first grader books. But Arda is 3th

> grader. Then Asaf asked why his brother is doing the first grade books although he goes to third grade. That time, I felt awful… Then we asked help from our counselor. They made sessions with Asaf for two months. But then Asaf told that he did not want to come to rehabilitation center again. We did not know why he did not want to go… but his behaviors towards his brothers became more moderate. He started correcting the mistakes of his brother and warning him, before he did not do these behaviors. He ignored his brother at home and he saw his brother as naughty, screamer and chatterer child… Now he starts realizing that he has a different brother. (Selma, G.63)

Hediye also saw the differences but not in regard to her mothering. She described the differences as behaviors and attitudes. She reflected the situation as:

> I act differently to him and to my daughter Selin. Because the former one acts as if he loses his connection with the world and he is a child who leans on me, trying to learn something and wants me to explain something to him. I do what he needs. But my daughter's world view is different. She is like my friend. Even she has ideas and opinions which are more mature than mine. Our communication is different with her. But if you ask mothering, it is the same. (Hediye, G.64)

Last 3 mothers Necla, Neriman and Mine agreed on the same opinion that rearing a child without disability and being the mother of that child was easier than child with disability. Necla reflected the differences as stating "it seems that rearing a child is easy with my other child Ali. If it is like this, I will give other births. It is so easy I cannot explain." (G.65) Neriman and Mine who did not have child without disability, described other mothers of children without disability as ungrateful and selfish. Both of them were angry at other mothers who did not know the value of their children. Mine depicted the differences between mothers of children with and without disability as follows:

> There are huge differences that I cannot explain… I realized that people show ingratitude toward what they have. They do not take a lesson. They do not thank for what they own… They cried out when their children have just fever. I asked them whether they saw me as an example. I did not sleep for 8 months… My daughter was given hormone to her brain. It was done for making slow brain get stronger. But it caused formation of oedema and oedema makes pains in body. Because of it, my daughter could not sleep because her brain did not sleep. I wasted time with her for 8 months without sleeping. I lost weight and became 35 kilos. My nervous system fell down.

> But even at a one time, I did not say me child why she did not sleep. I could not because I knew that she did not with her conscious. It was a hard period. They complain that the baby does not sleep, does not want breast feeding, and they get depressed. What do you want from God? You have a healthy child. After a time, s/he would turn to normal routine. When s/he is 2, s/he would tell his or her problem. Her diaper will be taken and s/he will say her or his needs. What do you want more? Until Canan was 5 years old, I was changing the diaper and cleaning her. I still do the same thing. It is not easy but other mothers cannot understand us. Even mothers with disabled child do not understand us too… while I was tolerating her child due to their disabilities, she does not stand my child. But you have the same example. If you act like this, how other mothers can understand us? (Mine, G.66)

To conclude, mothering a child with intellectual disability is different and challenging due to different reasons. These mothers feel the difference even in their home toward their children with or without disability and it may cause these mothers feel alienated to their mothering role. They are not typical mothers. But they are mothers or may be even more. There could be some confusion while they switch from their mothering of child with disability to child without disability.

Theme 6: Living with a Child with Intellectual Disability

In this theme, mothers were wanted to tell their daily life with their children with intellectual disability. Mothers listed their daily life requirements about their children. Because all children went to school, their day started with preparing their children for school. Then mothers went to school and 3 mothers stayed at the school until classes are dismissed. Their afternoon continued with going to rehabilitation center with their children and waited there. After special education lessons, most mothers joined activities such as swimming, basketball, going to park to play with their children. Then mothers dealt with housework and homework of their children. These are the common activities and daily program which were followed by all mothers in this study. This commonality may result from their all being housewives.

Common Problems in Daily Life

In this sub-theme, mothers were discussed whether they faced problems in their daily life with their children. Four mothers stated that they did not encounter any problem with their children and everything went normal while 5 mothers mentioned different problems.

Mothers having no problems told some difficulties but they did not describe them as problems. For instance, Melike mentioned about her daughter's adolescence concerns:

> We have difficulty even about dressing. Moreover, we have one more topic, hair style. We always have a fight for it. She does not tie back her hair, she doesn't want it. Her hair comes through her forehead and then hairiness started in her forehead. I told her not to do it because her forehead was scratched for brain surgery. In other words, we have no problem. (Melike, G.67)

As Melike, Hande had some desires from her daughter but she was pleased with her child as follows:

> Our day with Nazlı was pretty… I did not have a problem. ..But I want Nazlı to tidy up her room and she says that she will do it later. I wish she would tidy her room without my warning. For instance, when I go out, she cleans, sweeps home. Then she tells her sister to hide for making surprise to me. Or else, I do not have complaints from Nazlı. (Hande, G.68)

Filiz and Neriman also described their daily life normal and had no problem. On the other hand, other 5 mothers encountered problems with their children, but their problems varied.

Necla was complaining about her daughter's behavior problems although she was more pleased now with her daughter as follows:

> For example, I warned Betül not to talk to strangers. But she does not have a conscious about it. She may talk. She is sometimes asking nonsense questions. These behaviors are compelling me. Her behaviors toward her

> classmates were problematic but now she is more easygoing. But for a period, I had a bad time… She was scratching her classmates' notebooks when they did not play with her. She told that her classmate Ali did not play with her and she tore his book. I told her that this behavior was not appropriate and she should not do it… without a reason, she teased children and annoyed them. These behaviors knocked me out and made me tired. I was worried about receiving complaints from school… Now she grows up and she gets aware of something. I am more relaxed and like to have a good time with her. (Necla, G.69)

Aylin faced problems about stubbornness of her son and she said "our problem is his stubbornness. When he wants something if this is not done, he become stubborn… There are irresponsible people who made Utku angry. If they don't, there would be no problem." (G.70)

Behavior problems made also Hediye tired as Aylin and Necla. Hediye told that "Sometimes, he becomes so aggressive and nervous. At that time, I cannot trust him and I do not go out with him. He runs away in the road and he jumps through cars. He cries, screams and he acts as if he does not know me at that time. No longer, I live in fear of these." (G.71)

Mine was so tired because of the responsibility of her daughters and she explained her thoughts on this topic as follows:

> I encountered with their dissatisfactions. They get bored and want to go out. While Canan wants to go to the cinema, theatre and somewhere very social, her sister wants home visit. They have two different preferences due to their different characters. I experienced problems coming from this reason. Canan wants cake while her sister wants cookies. If I made the thing that former one wanted, latter one got bad tempered. If I made the thing latter one wanted, the former one got angry. If I made the both, I get exhausted. In other words, my life is not ordinary. I am so tired and that's why my brain was crashed. I am excessively tired… I have 95% of their responsibility while their father has 5%... I do not have any support… I am motivating myself on by own. I do not take energy from anywhere… I lost the most important supporters of my life for one year… My mother took the burden of my biggest daughter. .. For instance, my mother was going on a holiday with my oldest daughter and they went out together. When I burned out or got bored, she was my best friend who I was sharing my distress. Yeşim was my brother's wife. She was also easing my burden. The former was my right; the latter one was my left arm.

> Suddenly, they died within the next ten days. It was a disaster for me. (Mine, G.72)

Selma stated the problems they encountered and how she accepted them as follows:

> When Arda went to first grade, he had homework. I told that he should do his homework, brush his teeth, wash his hands and face, change his clothes and prepare his school bag by his own. These were at the first grade. I got bored. For two years, everything continued in slow motion. I changed his clothes, I brushed his teeth, dressed him up. We prepare his bag together because he cannot do it on his own. I think that he cannot do it. If he can, after my warning twice a day, he does. But he is not able to do it on his own. (Selma, G.73)

As can be seen, all mothers were dealing with different difficulties and they also took self-care of their children without any help. Only two mothers, Necla and Hande, did not deal with self-care of their children because their children could do it on their own.

Requirements of Being Mother of Child with Intellectual Disability

In this sub-theme, it aims to understand the different necessities to be the mothers of these children. Mothers were asked what needed for being the mother of their children. They did not think about this question and quickly listed what needed for being mother of these children. Four mothers mentioned about having full commitment to their children while 5 mothers emphasized importance of having patience. Also from these 5 mothers, 2 mothers highlighted to have the physical power to be the mother of these children.

Four mothers mentioned how they accommodated their life according to the needs of their children. Neriman expressed her opinions of being the mother of Ahmet as follows:

> Mother of Ahmet needs to experience life of Ahmet. If you want a special life for you, you neglect Ahmet. You should consider Ahmet in every topic. Your only program will be Ahmet. Everything you have is Ahmet. You should be

> only the mother of Ahmet. Beside it, if you try to be a friend, wife or other taken roles in your life, you neglect Ahmet. But I am trying to be in all of these roles. (Neriman, G.74)

Like as Neriman, Selma also emphasized her life which was identified with her son, Arda as follows:

> As the mother of Arda, you should carry your phone with you because you may have news from school at any time. He might pee his pants, he might make his clothes dirty while eating and his teacher may call you at any time. You should not go out for a longer time because you should be at home when Arda comes from school. When he comes home, he has some needs. He needs to go to special education lessons. His father leaves him at the rehabilitation center and I take him from here. Like other mothers, you cannot go somewhere after leaving your child to school. You cannot go somewhere for hours. You cannot call your friends and invite them to your house because he is so hyperactive and messy at home. When someone comes home, he does not leave you and asks many questions. When you go shopping, you should sort it out and come back. You cannot drink a coffee after shopping because he gets bored and wants to go home… It will continue for lifetime. You cannot leave your Arda and you cannot entrust him to someone and you worry about him. (Selma, G.75)

Melike and Filiz stated the same issue. Filiz explained how she was overprotective to avoid his son from any harm. She said “I should be more careful… For example, he should not receive a blow from his head. My overprotectiveness may come from this reason, in order to protect him from any harm.” (G.76)

Melike wished to have only one child in order to channelize her attention and committed herself to her child as follows:

> I wished I would not have my oldest daughter and I could take care of Burcu. But my oldest daughter has problems now. If I had a chance, I would have only one child. I would give my all attention to her. It is so difficult. I cannot go around both of them. (Melike, G.77)

These mothers put their children at the center of their life and they dedicated themselves for the sake of their children. They wanted to use their energy and attention to protect and fulfill the needs of their children.

Other 5 mothers indicated that mother of a child with intellectual disability should be patient and knowledgeable. Necla explained as being the mother of a child with intellectual disability and said “It needs excessive patient. Then it needs commitment. Moreover, it requires knowledge. You should be well-disciplined as the mother of Betül because she needs discipline, I know it. To sum up, it requires patience and commitment.” (G.78)

Likewise, Aylin described being the mother of Utku as:

> You should be educated. You should make empathy. To be the mother of Utku, you should be patient and sacrifice. You should understand him. If you don’t, it leads to bigger problems. Because he destroys something at home. In order to not to reinforce him, you should be like as friends. (Aylin, G.79)

Hediye exemplified the requirements of being mother of Doğukan as follows:

> Being the mother of Doğukan needs power. It needs patience, I think the most things you have is patience because patience is the biggest exam in life. I am patient but sometimes I cannot stand him. Our patience comes to an end. I am patient with Doğukan but sometimes I become inpatient and start shouting at him. (Hediye, G.80)

Mine put all necessities together and described being the mother of a child with intellectual disability as follows:

> It needs responsibility. Furthermore, it requires patience and being knowledgeable. I cannot say half but you should be “quarter” doctor. You should observe their behaviors. Canan is a very fat child. In order to make her have a bath, you should be strong enough. In short, you should be powerful in all aspects, physically and emotionally. (Mine, G.81)

It shows that being mothers of children with intellectual disability needed commitment, patience and strength to continue life in healthy way. Or else, they neglect themselves or their children because these children have more needs than healthy children do. In my opinion, they were rearing never growing up children, so they should be always the mother of a child although they become older.

Theme 7: Relationship with Their Husband before Diagnosis

In this theme, mothers were asked how their relationship with their husband before their children got diagnosis. Except Hediye, all mothers indicated that they had no significant problem in their marriage. They described their relationship with their husband as very good. Melike answered this question as “it was very good” like as other mothers. But Hediye had marital problems because of her sister-in-law. Hediye told her story as follows:

> Doğukan was born. My husband promised me that we would move to our own house after the birth. Then 40 days later, my husband told me that we would not go to our own house and we would live with his sister. The problem I encountered was told to my father by my relatives who witnessed this problem. My father called my husband. He asked my husband why we did not live in our own house. My husband did not show respect to my father. After this disrespect, I made my decision… I took Doğukan who was 40-day-old… When I went to house of my father, I said that I would get divorce. I told that if you want take care of Doğukan, do it; or else send Doğukan because I lost my passion… (Hediye, G.82)

Theme 8: Current Relationship with Their Husband after Diagnosis

In line with the purposes of the study, mothers were asked how their relationship with their husband now. This theme determined whether there were any differences in their relationship with their husbands over the years and how the child with intellectual disability affected the marriage. Four mothers told their relationship fall apart with their husband while 2 mothers mentioned first breakdown then reconciliation in their relationship. It was important to note that 3 mothers told that their relationship with their husband did not change and it continued better than the past.

Four mothers explained how their relationship brokedown started. Neriman mentioned how she returned from a horrible mistake and her marriage getting unimportant for her as follows:

> In our marriage, I did not hear any words except “my love, my life”. But our marriage became horrible. We had worse relationship but I still do not know why, I cannot answer it. We had bad times and we should have supported each other. But at that time, I should have kept Ahmet and also my marriage alive. To be honest, I did not care about my marriage. I should have kept a father for Ahmet. Then I came from hospital and told my husband what happened to Ahmet. He looked as if he did not pay attention to him. He saw the child normal. He acted as if there was no problem with Ahmet. We again argued with each other. Then he went to work. I wanted to relieve Ahmet’s pain and I took pillow and pills. We would sleep with my son. When I put the pillow, my sister called. If she had not called me, I would have smothered Ahmet… Then I cried and I got relaxed. I told my sister what happened with my husband. Then I made a decision. Our marriage was not important for me. It would be the same for my husband. I told my husband that our marriage was not important. You and I do not have luxury to die or become ill. We had a very good marriage for 18 years, now we would live for Ahmet… I can sacrifice you now, you are over for me. But you are not over for Ahmet because he needs a father … I chose the difficult one and I stayed for my child. We were trying to be good parents for Ahmet . We are not good partners. Now he is dying for me but where he was while we had trouble with Ahmet… (Neriman, G.83)

Necla and his husband had bad times due to the difficulty of rearing their daughter.

She explained her relationship with her husband as follows:

> When I cannot overcome the problems of Betül, I raise my voice. Our previous relationship was gone. I cannot say neither bad nor good relationship. But we do not have relationship as before. It was damaged; I can honestly say it… Betül makes me miserable within the day. She makes me tired because she repeats what she wants until it is done. She makes me tired in respect to taking something, going somewhere, going out etc. That’s why, I do not have patience. Furthermore, I get tired while doing homework with Betül. I ask for help from my husband. But he says that he cannot deal with it, I flame up. (Necla, G.84)

Hediye still had problems with her husband due to behavioral instability. She told that her husband becomes sometimes an affectionate father and an attentive husband. But sometimes he started an argument and she did not understand why it started. Hediye also complained about her husband’s allowing his sister to intervene in his marriage. She added that they always argued with each other but she tried to act as if there was no problem in order to not to make their children sad.

Filiz mentioned that their relationship with his husband did not change after the diagnosis of Mert and they got on well with each other. But then they divorced resulting from not Mert.

But every marriage did not go that bad. For 3 mothers, their relationship became better after the diagnosis of their children and now they had good relationship with their husbands. Aylin told that they loved Utku and they did not have problem due to Utku. Although her husband died 3 years ago, she remembered her husband as a nice partner. Hande also stated that their relationship with her husband was better now and they enjoyed having time as a family. Selma expressed her thoughts about her husband as follows:

> Our marriage was good and still continues well. Arda is our reality and we accepted him. We live our life not according to us, een not according to our little child Asaf. Our focus is Arda. But it does not create a problem for Levent and me. We leave our children to our mom and dad and we go to the cinema. We spare time for each other because either my husband or I get tired and bored naturally… As I said we are happy, thank god. (Selma, G.85)

Some marriages went worse due to imbalance in the family but then they became happy with their children. Melike told what she experienced when Burcu was a first grader:

> When I was trying to teach reading and writing to Burcu, he shouted at me so much. I also shouted at Burcu because she did not read without my warning. I got angry and told her to read it. My husband was telling me whether I would make Burcu a lawyer. He wanted me to leave her alone. But I told that she must do it. If I died, she would know how to take her pills and go to hospital. If she did not know reading, how she would manage it. Who would take care of her? What happened if no one took care of her after my death? What if her sister did not take care of her? At that time, I struggled. She did not do her homework and I was waiting until it ended. But now my husband is very nice to me. (Melike, G.86)

Likewise Melike, Mine experienced the same process but her husband became a big change after he accepted the diagnosis of his daughters. Mine was telling this change as follows:

> I accepted my children from the beginning. But my husband had trouble with them and he became addicted to alcohol. In addition to my two daughters, I tried to deal with my husband. We have still problems. But in contrast to the past, we are very good but he had great difficulty… He was addicted to alcohol. He came home late and spent time with his friends. Besides, he was so nervous and angry. He did not prefer to go anywhere with our daughters… at the beginning, I supposed that he felt shame from our children and he did not accept them. In process of time, we stopped being partners and we became friends. I realized that my husband was crying secretly like a child when our daughters became ill. When our daughters tried to walk, he was sweating because girls' having difficulty in walking hurt my husband so much. I realized them later… Before, he did not tell anyone that he had disabled children but now he expressed it freely… Thanks god, now we are happy. My husband tells that you are able to manage all of us… He has worries about losing me… When I am not there, they become unbalanced because I am at the center of their life. I am managing lots of things. I am like an octopus. My arms reach everywhere. It must do it. Because I understand that I become weak, I start using antidepressant. (Mine, G.87)

In conclusion, having a child with intellectual disability changed their family dynamics and relationship between partners in positive or negative ways. But it could be said that having this kind of child made them tired physically and psychologically. This tiredness might affect their relationship with their husbands in negative ways. But when they have a support system, like in the example of Selma, their relationship may become stronger and healthier.

Theme 9: Expectations from the Future regarding Their Children

In this theme, mothers were asked their expectations about their children from the future. 5 mothers indicated that they had no expectations while other 3 mothers expected their children to get education and have a job. In addition to these mothers, one mother Neriman, expressed that she did not have expectations, she had dreams about her son.

Five mothers looked at the future pessimistically and they came up with different reasons. Hediye did not have expectations and thought that it was early to expect something from her son. She expressed her thought as follows:

> It is a difficult question. I think it is so early to expect. Before anything else, Doğukan should wake up to himself and calm down. For the future, of course I want him to get education but if he cannot, I will not be sad. If he lives without harming himself or other people, it is enough for me. I do not want anything. University or high school, I do not think of these. (Hediye, G.88)

Necla also stated she did not have expectations from the future but:

> I do not have many expectations but if she graduates from high school, it is a big achievement for me. It is as if she graduates from university and becomes a professor. I do not have such an expectation. If she graduates from university, she might get a job for to save herself. We don't want anything else. These children do not have academic things but if she might have a job and work, it is good. (Necla, G.89)

Melike did not have future expectations because she could not trust the ability of her daughter:

> I don't have a future expectation for Burcu… I don't know; I feel that she cannot do… I do not know whether she can marry and keep house. When she works, she is able to do but I do not know. Time will show what will happen. But sometimes I tell Burcu that she will marry. Even I say to my oldest daughter that she does not help me to experience grandchild's love. Then Burcu told that she would do it. How do I know? (Melike, G.90)

When Mine was asked about her future expectations, she expressed her worries instead of her expectations first as follows:

> I have a high anxiety. If I die, what would happen to them? This is the only worry in my life. Because of this reason, I bag God not to leave us from each other… I do not have expectations. It continues for the duration… but I want something for the future. I wish their seizures will be recovered. This is my biggest desire from God… I do not have special expectations such as their being healthy, getting married, having children. I frosted something in my heart. I know what can happen and what cannot be. Because I am conscious about it, I do not dream about having these. (Mine, G.91)

Selma also did not have expectations because she thought that without education, these children could not have a future:

> I do not expect something but there is something that I really want to do. I believe that with education, everything will get better. With education, every problem can be overcome. With social activities, this disability can be decreased. But because of the procedures, there is not much things you can do. They just go to public schools and get education. I do not expect anything

> from the future because if you want, you should do something for the future. You cannot expect something without making effort for it. (Selma, G.92)

On the other hands, Hande, Filiz and Aylin expected their children to get education because they wanted their children to have a job. They had also the same worry about what happened when they died. Due to this reason, they wanted their children to take care of themselves.

But Neriman had dreams for Ahmet but she was experiencing disappointments when she faced the reality as follows:

> I have lots of expectations from the future for Ahmet. His getting married, having children, having a job… but these are dreams beyond expectations. They are my desires. I am struggling for having these desires. Then when we get into public buses, I see strange behaviors of Ahmet and it takes all my power away. When an old person sits near him, he might say "please stand up, I will sit here". Normal children do not say it. These behaviors made me unhappy. I do not want him to tell it. I talk with Ahmet and explain that because she is old, he should give his place. But he says that he wants to sit… (Neriman, G.93)

In my opinion, future did not make these mothers happy or hopeful because they had a common worry about their dying and they constantly asked themselves who would take care of their children when they died. Because they did not have answer, or they had answer which did not satisfy them, they looked at the future pessimistically. Their most important expectation for their children was to get a job and save themselves. On the other hand, they did not trust that their children could achieve it.

Theme 10: Messages to Mothers

In this theme, mothers were asked to give their messages to other mothers as having a child with intellectual disability. In scope with the study, this question was asked with the aim of seeing the common wishes or needs of mothers of children with intellectual disability. Three mothers gave messages to other mothers' expressing gratitude to their healthy children, 3 mothers about never giving up struggling and 2 mothers about eliminating stigmatization of disability. Furthermore, one mother, Mine, expressed both expressing gratitude to their healthy children and 4 mothers put a heavy emphasis on knowing the value of having a healthy child. They thought that mother of a healthy child was very lucky and she should have expressed her gratitude for her child. Aylin expressed her opinions regarding to having a healthy child as follows:

> This is my message to other mothers; they should know the value of their healthy children because it is very important. All children are our children. Most healthy children have behavior problems. Mothers should take care of their children because if this child is healthy, he can understand everything, do everything. As long as they have intelligence, rest of them is not a big deal. Raise a child well, he or she will be a good person and beneficial to you and society. (Aylin, G.94)

Neriman was angry with other mothers who did not know the value of their healthy children and indicated her messages as:

> How lucky other mothers! In other words, they are thankless. That’s my way of thinking. For instance, the child has no problem but his or her mother might make their children sad for an unimportant thing. They leave their children in order to chat with their friends. I feel sorry for it. I see children who need love and attention but their mothers continue chatting with their friends. These mothers do not look at their children. They do not pay attention to children… Or their children are healthy but they don’t pay attention to their education… they are so lucky. They have jewel in their hands but they do not know its value. By the way, do I evaluate myself as unlucky? No, after Ahmet I had a quite different life… (Neriman, G.95)

Necla also reflected the same issue and warned other mothers about being happy with what they had and expressed gratitude for having their children.

Other 3 mothers emphasized on not giving up struggle for the benefit of their children with disability. After this question, these mothers gave messages to mothers of children with disability so their messages focused on going on being patient and trying for progress of their children. For instance, Melike said “my advice to other mothers of children with disability is not to give up struggle. My daughter progressed till the point that was said it was impossible. There was a big progress. I am still hopeful and happy.” (G.96) Moreover, Filiz came up with the same opinion and she said “They should support their children and stand back of them. They should not leave them alone.” (G.97)

Likewise, Hediye gave her messages as follows:

> Everything is difficult for the person suffering from it. In any case, we need patience, in my opinion. They should show patience. There are such mothers who give up their children, were deeply occupied with their own trouble and leave home. Do you know that I cannot accept these mothers? Whatever the consequences, they should not give up taking care of their children. I cannot tell any other thing. (Hediye, G.98)

Other two mothers needed getting respect from other mothers and not feeling stigmatization of their children with disability. Selma described the situation as follows:

> These children belong to all of us, both with or without disability. I think they have both rights. Scrutinizing, warning or excluding these children is meaningless because attention deficit can be seen in every age. Beside, being disabled or being a mother of child with disability can be faced in every age. They should look at the situation optimistically. Other mothers should not prevent their children to make friendship with children with disability. They can be friends. For example, some mothers tell that their children are negatively affected; they do not see my child with disability. There should not be such an attitude. These mothers should teach their children that our children have different characteristics and they are different and they warn them about their possibility of having a disability at any time… ın short, we should accept all people as they are and show respect for them because we all want the good things and how we look, we see in this way. (Selma, G.99)

Hande also expressed this stigmatization but told that:

> I do not see my daughter worthless than other children. In my eyes, she is equal to other children. When I see her, I do not realize any deficit or fault. But it is my opinion. Other mothers might perceive her different and negative but I do not have such an attitude. (Hande, G.100)

Mine blended all messages and told other mothers as follows:

> Mothers who have normal children should thank to God for thousand times. I also thank God for having such special daughters. I do not have a special message. Only they should know the value of wealth in their hands. Also, when they see us outside, they should show endless respect for us because we experience 3000 times more difficult thing than they do. I think we are 3000 times more mother than other mothers… I think we do not get respect. I suppose that other mothers are more thankless. As saying not getting respect, I mean they do not understand us. But there are many people who understand us, too. For example, my husband's cousin had told me that he could not understand how a mother I was because I dedicated my life to my children. After years, he became a father. He now tells "aunt you are right, I understand you now. Having a child is quite different feeling. Moreover, mine is healthy, yours are unhealthy". But from my side, there is no difference. My daughters are children like as 10 healthy children… they are my daughters but when I face such a person who is talking like this, I feel that they do not show respect for me. (Mine, G.101)

In my opinion, with these messages mothers again emphasized their lives were quite different and difficult so that they felt that they had more mothering than other mothers. In this struggle, they were waiting respect and making their children included to the society. For the mothers of children with disability, they put heavy emphasis on trying for the progress of the child with disability and not leaving them supportless and alone.

Theme 11: Influences of a Child with Intellectual Disability

In this theme, mothers were asked how the situation of their children influenced them as a family. With this theme, it was aimed to comprehend whether their family system was affected by having a child with intellectual disability or not especially their reaction to a family member. Also, it indicated how they reacted to the member having intellectual disability in the family as well.

Analysis of data revealed that 5 mothers' family was affected negatively by having a child with intellectual disability while other 4 mothers indicated that their families were not affected by their children's disability. Mothers who told that they were affected by their child with intellectual disability pointed out different reasons for this situation. For instance, Neriman expressed how her marriage was deteriorated and she and her husband made a decision about not dying, not being ill for the sake of their son. Their family dynamics were negatively affected while dealing with the needs of their son having intellectual disability. She shared that her husband still cried for the situation of his son. Then Neriman dedicated her life to her son and she did even have plastic surgery for her beauty with the aim of being loved by her son and being a young mother for her son. She mentioned her thoughts as follows:

> I wish Ahmet will not be different, now my life is so precious. I should not die, or be ill. Now I am taking vitamin pills, I care for myself very well. Why did I have a plastic surgery? Because Ahmet gives importance to beauty very much. He loves me so much… In other words, I want to be a young and strong mother for Ahmet. I want to live long and healthy in order to bring him up to standard. (Neriman, G.102)

Likewise, Aylin was the one who was affected by having the child with intellectual disability in the family like Neriman. Her life also changed and she lost her contact with friends. She told the situation as follows:

> After Utku's situation started, my relationship with my friends and my social environment fragmented because I just focused on Utku. I gave all my attention to Utku with the thought that I might have taught him something, he might be better and I might have filled the gap through educational services. I got alienated from my social environment. In the beginning, I could not overcome the situation. People have some resentment when they have children with disability. But now I am comfortable with Utku…. I go to everywhere with Utku. (Aylin, G.103)

Hande stated that her husband was negatively influenced by the disability of his daughter. She said how her husband reacted by saying "why it happened while everything went normal. Why everything was okay. She did not speak and she became ill?" (G.104) Although her husband got sorry for her daughter and asked why it happened, Hande accepted the situation because she believed that it came from God.

Melike also told that they were shocked at the beginning as a family. Because her daughter needed much more attention and care, Melike gave all her attention to Burcu alone. Her husband could not did it, so Melike's mother helped her daughter for her struggle. But she added that at the present they were having positive attitudes toward the disability of Burcu.

Hediye was the mother who understood her daughter could not accept the situation of her brother and was badly affected. She indicated how her daughter was influenced by the situation as follows:

> For example, the situation of my son affected my daughter negatively. She keeps a diary and sometimes I read it secretly. She does not want me to read but she does not lock. In my opinion, Selin was affected badly. We somehow come to a stage to accept the situation. Personally, I accepted the situation. Also, my husband is trying to accept it. He is about to accept. But Selin looked as if she accepted the situation although she did not. For instance, she wrote in her diary" dear diary, my brother is experiencing something and he does not know us; I cannot stand it. "Will not my brother recognize me?" She wrote something like this a week ago. Yesterday, she wrote something that I very liked. I suppose she is trying to accept her brother. "Dear diary, my brother is ill. My mother is very upset. I will just stand for my brother. I will bear to support my mother and my brother. I am about to fall down but I am going to stand." I was moved into tears. I asked Selin to give permission me to read her diary and asked her when I would read it. She told that I would never be allowed to read it but I read sometimes and like the things she writes. (Hediye, G.105)

While mothers mentioned above expressed how they and their family were affected by the disability of their children, 4 mothers thought that they were not affected by the situation. Filiz mentioned that nothing changed in their family after the disability condition of Mert. She thought that Mert was not different from her other sons.

Necla also stated that no one was affected by the situation of Betül because nobody in her family believed that Betül had intellectual disability. According to Necla, no member in her family was aware of the situation.

Selma had a different perspective. She thought that they were not influenced by the situation because:

> We were not affected. I think about what we can do in these circumstances. I did not complain about why it happened. We were never affected. We considered about we could do, how we could be beneficial. My own family asked us how they could do for helping us. They also asked whether there was anything they should have known or done… my family and my husband's family, we all look at Arda with love. We are trying to ignore his negative behaviors and trying to correct him. (Selma, G.106)

Lastly, Mine expressed that they were not affected by the situation of her daughters. On the other hand, while she was talking about her life, she pointed out how she became tired and exhausted. She told that sometimes she did not have time to look at the mirror. After an intensive tempo of day, in the evening she became exhausted. Also, she mentioned that her husband became addicted to alcohol after the disability of their daughters. Although she told that they were not affected, physically and emotionally she and her husband was badly affected from the situation.

Contributions of Having a Child with Disability

In this sub-theme, mothers were asked what this situation of their children contributed to their life. This theme aimed to show whether they gained something from the negative situation and they could see the positive sides of the disability.

When mothers were asked whether they gained something from the situation, only Filiz told that she did not gain anything. She thought that the disability of her son neither took away nor gained something for her or her family. In contrast to Filiz, other 8 mothers put a heavy emphasis what they gained something important for their lives. Their responses varied but their answers were consisted of gaining optimistic view, expressing gratitude, being strong and patient, enjoying their life and strengthening their spirituality. During the interviews, mothers highlighted these positive contributions of their children's disability. For instance, Selma was indicating her increased awareness about disability and thinking in optimistic way as follows:

> For example, my aunt's son has intellectual disability and also he cannot hear and speak. He was the only child having disability in my family. After I married, I saw Arda's uncle has physical disability. but we did not know anyone else having disability around us. After Arda got diagnosis with intellectual disability, I realized that there are students in inclusive education in his classroom; they were alive and living around us. For instance, when we go to the park, although a child looks normal physically, I can understand his or her differences from their behaviors. I mean, they do not have physical but mental disability. You get aware of them. You see them… When facing with children in worse situation than Arda, I tell that Arda has no problem and with education some problems will be overcame. You become hopeful when encountering the worse ones. I have learned to look positively and see positively… I have never avoided taking Arda to social activities. My friends and people around me appreciated me for my efforts. As you are appreciated, you become hopeful and motivated to do something more. But when people say bad things and criticize you, you get disappointed and withdraw because being a parent of a child with disability is very hard. Your burden is very heavy. You should struggle with anyone; you struggle with glances around you. When someone tells something bad, you become miserable because being a mother of a child with disability is that your one part is always broken in your hearth. (Selma, G.107)

Aylin also looked at the positive side of having a different child. Because everyone knew and loved Utku, she enjoyed the situation. She felt that Utku gave pleasure and enjoyment into her life.

Likewise, Hande had optimistic view and she thought that having a child with disability taught her to express gratitude and see the glass half full. She told that Nazlı could have had a worse disability.

Hediye felt that her family turned to its normal routine because Doğukan was in better condition in contrary to last year. Because of this reason, she became happy by comparing his development and progress. Her husband, her daughter and she recognized how Doğukan progressed within years and they became hopeful by focusing the competences of Doğukan he gained.

Like Hediye, Melike and her family became happy when Burcu started moving, walking and learning toilet training because her doctors told that Burcu would never walk, talk and she would lie back. Furthermore, she added the contribution of living a child with disability as follows:

> I have learned lots of things due to Burcu. I learned to struggle with life and know people. I faced many types of people and know who can harm us in hospital. Now I became a judge of character and can read people… Burcu had the benefit on me. I did not know the atmosphere of hospital, how to go and fulfill my needs. I could not speak with doctors. Until doctors asked me one by one, I could not tell. Now, I get to know medicines, which medicine is useful for which illness, which department I should o in hospital for specific problem, which doctor is the best in this department… My network becomes enlarged. (Melike, G.108)

Necla expressed her thought about what she gained from the situation of Betül as follows:

> Now I think that there is nothing that I cannot for Betül as a mother. I can do everything. I can do everything not for Ali but for Betül. She also taught patience. She taught me to love much more. I learned to be more compassionate… Now I feel more powerful. Disability of Betül does not make me helpless. That's what I mean. Now I am crying but I did not get on top of Betül. Now I am stronger and gained more power. (Necla, G.109)

Moreover, Mine realized some differences in not only herself but also her husband:

> My husband was very different man who spent most of his time outside… He did not have an understanding family orderliness. Then he became a family man… He became very merciful. He shows mercy toward children. His faith becomes stronger. He learned that no one can do anything without God's permission. His faith was not strong before. Then my daughter started walking suddenly and unexpectedly. He understood it happened with God willing… Furthermore, I learned to be a human. I did not love children before. Do you believe me, now I love even "gipsy" children? I become a human, there is nothing more. Beforetime, I was very thoughtless. I was looking absently but now I am not looking. I learned to observe everything and I can understand them. (Mine, G.110)

Neriman also thought that she and her husband learned something from this experience. She reflected her opinions as follows:

> It contributed lots of things to my life. He opened the eyes of my heart…Ahmet lends color to my life. Life is more beautiful, he makes me love living. Now I see the world many times more pretty than before. Every morning I dandle the roses in my garden and I express gratitude. I become a person who observes every detail. When I look at something, I thank God for it. When I look at them, I wish Ahmet health… I know that God is with us. I believe that it is an examination so that I can live strongly. I believe that this will be finished on day and God will give our prize. (Neriman, G.111)

To sum up, every mother understood how they became stronger after the disability of their children. They became more aware of the life and its importance. They seemed to be trying to be happy as much as possible. In my opinion, their analyzing what they gained from having a child with disability showed their coping system. Most of them used the spirituality for instance. They focused on the positive sides of their children and their life. This indicated that although they were psychologically and physically tired, these mothers got some positive values for their life as well.

CHAPTER V

DISCUSSION

This section included the discussion of the findings along with conclusion and suggestions. Moreover, limitations of the study and recommendations for further research are presented.

This study examined the life experiences of mothers who had children with mild intellectual disability. The research study was conducted by the means of in-depth interviews with nine mothers whose children were diagnosed with mild intellectual disability. The data was analyzed by the researcher using thematic approach, in which the data was identified, analyzed and divided patterns within the data.

In this study, there were nine mothers who were between the ages of 33 and 56 years old. In line with the purpose of the study, these mothers had at least one child having mild intellectual disability. These children were between the ages of 7 to 15.

Not surprisingly, mothers had similar life experiences in general but their perspectives to their lives were quite different. While some mothers had more optimistic view and closer to accepting disability condition of their children, some had difficulty in accepting this situation and had more pessimistic view. These findings would be explained by starting from the mothers' own lives and expanding to their family and society.

Pregnancy

When data were analyzed, it appeared that pregnancy process was not so different for mothers of children with intellectual disability than mothers of typically developing children. Although some mothers had health problems during prenatal period, they did not reflect it as a problem. Mahoney et al. (1992) emphasized that mothers of children with disability shared many common experiences with mothers of children without disability (Pelchat, Lefebvre, & Perreault, 2003). It could be speculated that mothers who faced some problems or symptoms of disability did not want to see these as a problem because they might have a hope that it could get better or disappeared very soon. The prenatal period was the beginning of their pregnancies and they may have difficulty in believing the existence of a disability in their baby because in pregnancy mothers generally focus more to the having a baby rather than possibility that their unborn babies have. But after the baby is born and his or her disability become apparent, mothers see the situation and possibility of not escaping, they will believe that their children have a kind of abnormality. This awareness might not belong to pregnancy period because it is full of expectations and dreams about the unborn baby as Necla expressed as “I was expecting kind of things that all parents expected from their babies… All parents become happy when they learned to have a baby. They dream about their children’s future and his or her going to school” (G.112). In this dreaming period, there might have no space to think about negative possibilities about the baby. Therefore, it might be a kind of denial and mothers might want to remember their pregnancy positively as the mothers of typically developing children.

Biopsychosocial Model

During the interviews, mothers were talking about the disabling condition of their children and mostly they described their children as “unhealthy”. They saw the disability as a biological dysfunction that comes within the child. When mothers in this study talked about other children without disability, they used the term “healthy children”. They told that their children lacked some abilities so they, as mothers, provided protection and care for their children with disability. It showed that mothers in this study generally approached the issue of disability from a more medical point of view which was similar to the findings of another research study in Turkey (Sevim, 2011). According to Arıkan, medical model saw the disability as a kind of pathology and focused on the disability itself, not the person with disability (Sevim, 2011). Because of this approach, all people with disability are assumed to be “inadequate”. On the other hand, there was a mother, Selma, who explained her son’s disability from social model perspective. She thought that her son’s problem resulted from absence of educational and social services which were forgotten to fulfill her son’s needs. When her son received special education services, therapy and had his legal rights, she assumed that her son could get included with the society as social model advocated (Arıkan, 2002). Two different models explained the disability from different views but they had some lacking parts. Because of this need, ICF (International Classification of Functioning) used “biopsychosocial approach” in order to integrate social and medical model for increasing functioning in disability (WHO, 2001). According to biopsychosocial model, disability could be understood as an interaction between medical factor and contextual factors which consisted of environmental and personal factors (WHO, 2001). In this context, disability was not only a biological dysfunction as the mothers in this study believed. Rather seen as biological or medical dysfunction, their children’s activities got limited and they had difficulties in their individual and social lives. In my opinion, the view of mothers in this study towards their children’s disability might have an influence in their acceptance level of disability and their tendency to seek help because they thought that it was only their problem to have a child with disability which closed their channels to get services from society.

Being the Mother of a Child with Disability

Another finding which was revealed from data was that all mothers in this study organized their lives according to the needs of their children with intellectual disability and their only focus was their children with disability. Although they had a spouse and another child; they did not pay attention to their other roles such as being a mother of their other children, being a wife, neighbor etc. They also accepted the belief that when they had another role such as being a wife, a friend, or a neighbor, they would neglect their child with disability. The possibility of neglecting their children with disability weighted more than neglecting other roles in their life. Neriman put the dilemma with her son into words:

> Ahmet’s mother must live the life of Ahmet. If you want a private life, you would neglect Ahmet. You should plan everything by considering the needs of Ahmet. Your only program should belong to Ahmet. You should be only “mother of Ahmet”. Beside this role, if you try to be a wife, friend etc., you neglect Ahmet and his needs.” (Neriman, G.113)

They acted as if the child with disability was their own property so they were taking the whole responsibility of their children. Accordingly, Sevim (2011) explained that mothers of children with disability held themselves responsible for having this child because the baby they gave birth was not good enough to make the family happy. I think this irrational belief might increase the mothers’ tendency to see the child as their own property and identify themselves with the mother of this child. Although none of the mothers in this study expressed the feeling of inadequacy directly, it could be an underlying reason of owning the child with disability excessively and possessively.

Social Network and Support

Findings showed that mothers in this study did not have an extended support network which was different from research findings in foreign countries (Gardner & Harmon, 2002; Stainton & Besser, 1998). According to Dunst et al., utilized model of social support consisted of four categories named as immediate family, kinship network, informal network and professionals and organizations (Correa, Bonilla, & Reyes-MacPherson, 2010). This model asserted that optimal family functioning is related to broader range of sources of support which helps well-being of family (Correa, Bonilla, & Reyes-MacPherson, 2010). When looking at the each category of social support, mothers in this study had little sources. It is interesting because in Turkey kinship is very important and people in Turkey like being connected with people around them which provide social support. However, these mothers' social environment is limited to their family members, own parents of mothers, siblings and medical doctors. They had little social interaction after birth of a child with disability as other research studies showed such as McConkey et al. (2008) and Günsel (2010). Mothers generally stated that they got help from their mothers, siblings or husbands. In my opinion, decreasing social network in this study may be related to social view to disability. Mothers mentioned that they were most comfortable with their children having disability at home alone. When they got outside, they should deal with their children to control them and also explain the behavior abnormalities of their children to society members. Selma mentioned why they needed to explain the situation of their children to society as follows:

> When we get outside with Arda, there were difficulties waiting for us. Because Arda looks like a normal child physically, people expect behavior which they expect from a normal child. But Arda might act strangely and make different noises by shouting. If you are at a dinner or in a mall, all eyes are on us. Even other people do not look at us, I feel that they are looking at me due to strange behaviors of Arda. (Selma, G.114)

This might create withdrawal from social contacts for mothers of children with disability. Furthermore, because mothers in this study are the primary caregiver of their children, they might not have enough time to spend for their social lives.

Although the findings showed that mothers received little help from their social resources, even little help increased their well-being. For example, Selma and Melike emphasized their mothers’ help to care their children with disability and how they had opportunity to take a short break. Due to support of her mother, Selma had a time to spend with her husband which maintained their marital relationship. But after losing her mother and her best friend who provided support for Mine in regard to household duties, caring child for her when she was down. She described her condition as “after losing my mother and my best friend within the same year, I fell like a deflated balloon. My daughters and I were left alone”. (G.116) Then, Mine was diagnosed with “depression” and had to use medications for her depressed mood. Accordingly, Günsel (2010) emphasized that as the social support and perceived satisfaction from support increase, symptoms of depression lowered.

Negative Attitudes of Professionals

As mentioned before, one of the categories of support, professionals and organizations, could not achieve its role to help the families of children with disability. For instance, none of the mothers in this study was affiliated to an association working for the people with disability and for their families. There are some associations for people with intellectual disability but these mothers even were not aware of the existence of these organizations. As stated by Dunst et al., it is a precious support resource however it is neglected in our country which shows the situation of disability regarding NGOs or advocacy in Turkey (Correa, Bonilla, & Reyes-MacPherson, 2010). Disability and disability rights are thought as new topics in Turkey because advocacy of disability rights gained importance after the declaration of Turkish Disability Act in 2005 (http://www.ozida.gov.tr). This law covered people with disability, their families and organizations which will serve to fulfill the needs of these people. Through this law, it was aimed to remove obstacle in the lives of people with disability with regard to education, health, care, rehabilitation and social security areas (http://www.ozida.gov.tr). After the rights of people with disability were guaranteed by laws and NGOs started their working for people with disability and their families. Because it is a new source of support in Turkey, it is not commonly used by most mothers of children with disability similar to our study. Furthermore, mothers were complaining about the professionals who (i.e, early interventionist, physician, child psychiatrist, and teachers) made the situation worse because professionals did not help the mothers to understand the situation of their children, treatment and education of the child. It was very important how to explain the situation of the child with disability to his or her family because it shaped the acceptance process of the family. Mothers in this study mentioned that they were not informed about the features of intellectual disability. Aylin told how the doctor explained the disability of her son as follows:

> They told us that he would follow his peers one or two years behind. It was told that he could learn something by through formal education. At that time, we could not understand the situation of Utku correctly. I assumed that this disability could be cured by education. (Aylin, G.115)

This explanation did not give any idea about what would happen to their children in different developmental stages, how they would be educated, how mothers would reach social support resources and use their rights for disabled people. As Vural (2010) discussed that attitudes of medical doctors who explained the diagnosis of children with disability, giving emphasis on strengths of children and their ability to be developed, how families could get help for family therapy or group counseling had an positive effect on hope of families. When the attitudes of medical doctors, teachers or other professionals were negative, mothers had difficulty in accepting the situation and they also developed negative attitudes towards the situation of their children (Ersumer & Grimes, 2013). In this research study, it was understood that negative attitudes of professionals, especially child psychiatrist and classroom teachers of children, had an effect on mothers' experiencing "suffering or depression stage" and lack of information about disability made the denial process of mothers take longer. As in the example of Aylin, she was given a hope that her child's disability could be cured by education but it turned not to be true and this made the mother disappointed for this mother later on.

Perception of Mothering Identity

Moreover, mothers in this study perceived their children's disability as the only problem in their life. They thought that parent of typically developing child did not experience problems as much as they did although most mothers in this study also had typically developing child. They did not accept other mothers' caregiver role as motherhood. Mine gave voice to this thought as "…we experience 3000 times more difficulty than they do. I think we are 3000 times more mother than other mothers." (G.117) On the other hand, Mahoney, O'Sullivan and Robinson (1992) highlighted that mothers of children with disability and mothers of typically developing children shared many positive and negative experiences in common because many experiences resulted from commonality of family life in general (Bower& Hayes, 1998). According to research study conducted by Green (2006), mothering a child with disability was exhausting, demanding and time consuming but it was not different from ordinary parenting. This assumption may increase their sense of mothering and give them strength to continue their caregiving by glorifying their role. It seemed to be a kind of coping mechanism in order not to give up this continued caregiving.

It was also found that mothers gained different strengths from being a mother of child with disability. They started fight for their children with disability. For example, Hediye who could not get divorce in despite of all troubles in her marriage and stood her husband, outfaced her husband to get medical report for his son. In another example, Neriman kept the leading position and did not get divorce because she wanted her husband to be the father of her son. This was in line with the research of Cramm and Nieboer (2011) in which they found out that mothers overlooked their own negative conditions and well-being in favor of the child with disability. I consider that it might be a kind of advocacy because these mothers did not seem to be strong enough to fight before having their children with disability. But after this child, they might have gained different mission in their life for their children.

Caregiving

In this study as the findings pointed out, middle childhood was very difficult period for mothers of children with disability. Mothers whose children reached adolescence or became closer to this period expressed that they were more comfortable than the past. The data was consistent with the findings in other research studies (Clifford, 2007; Dura-Vila et. al, 2010). Moreover, Günsel (2010) stated that mothers of children with disability were most stressful when their children were in middle childhood between the ages of 7 to 13. This situation might come from the more adaptable behaviors of their children which were increased by help of special education services. Another reason may stem from mothers' learning more effective parenting techniques for the needs of their children in time. Necla highlighted the progress in her daughter as she grew up as follows:

> When Betül learned reading, I became very happy. Although she cannot read fluently, she at least does something by herself. Last year, I got bored while making her doing her homework. I gave up my other duties and even my other child and I devoted my time to make Betül study. But this year, I am more comfortable in regard to her lessons. She wants to study at least. When I see these things, I get more relaxed. My anxiety lowered. Beforehand, I worried more for her… Now, I can go anywhere with Betül more easily. I am better now because she is more controlled in her behaviors. (Necla, G.118)

In line with this study, it was important to note that mothers did not want to share this responsibility with anyone. They committed themselves to this responsibility and expressed how happy they were from this mothering. Although they had difficulty in providing the all demands at home, they avoided to express any negative feeling for experiencing this situation. Neriman expressed how she felt pleasure of being the mother of her son as follows "being the mother of Ahmet is very pleasant. If I was born for 1000 times, again I would want Ahmet as my son. I would not want another child." (G.119) The happiness from being mother of this kind of children provided energy to these mothers. According to Rowbotham et al. (2011), mothers felt more satisfaction when they spent more time in providing caregiving. I think it may be also another way of glorifying their sense of motherhood.

Fathers vs. Mothers

Throughout the interview, mothers expressed that they were the primary caregiver of their children with disability, so that they could have more caregiving difficulty than fathers did. Because there was not enough division of labour at home, from the point of mothers, mothers carried more caregiving burden than fathers. Research studies also supported that mothers spent more time in caregiving than fathers (Meral& Cavkaytar, 2012). Furthermore, when mothers asked their husbands for help them to care their children; they were unwilling to share this responsibility as it was also discussed by Ersumer and Grimes (2013). Mine gave example from their daily life as follows:

> My husband is not aware of needs of children from the eyes of mother. I am responsible from giving my daughters' medications, helping them to take bath etc. They are even playing with their father. But after a time, my husband says to my girls "do not speak! Let me have a look at football match". But I cannot say my girls "Canan please I will watch soap opera" because when she gets angry, I would go after her to make my daughter cool down. (Mine, G.120)

Beside, another research showed that mothers tended to exclude father from caregiving of their children (Pelchat et al., 2003). In my opinion, because of this unwillingness, mothers might have more tendencies to take more and more responsibility and they dedicated their life to their children with disability. It might be also speculated that they were not sure about the caregiving ability of their husbands, and due to this reason they may exclude fathers from this role although they need help.

With regard to fathers' approaching their children with disability, mothers felt that their husbands had difficulty in accepting their children. During the process in which medical and educational reports of disability were taken, mothers tried to persuade their husband that their children had some difficulty. For instance Necla mentioned her struggle of making her husband accept that her daughter had a disability as follows:

> My husband did not accept the disability. I was telling that this child had a problem but my family members told that I was exaggerating… When my husband took Betül to hospital for diagnosis, it was decided that her mental process was normal. Therefore, my husband complained that I was exaggerating. Then, we went to hospital again but we were given the same diagnosis…Then she was taken Denver developmental test. Her test result was again normal. Her disability was not diagnosed easily. (Necla, G.121)

As the process of getting medical report of disability went longer, as mothers reflected, their husbands' assumption of their children's having no disability was becoming stronger. After the disability report was taken, from the eyes of mothers, fathers less likely showed their emotions and took responsibility for their children. These behaviors made mothers think that their spouses did not accept their children. Furthermore, it was also emphasized by Pelchat et al. (2003) that fathers had difficulty in accepting the disability itself. Due to this reason, they had less likely showed their emotions about their children because that would mean seeing the difference in their children. While mothers were dealing with the demands of caregiving of their children with disability, fathers were struggling with the idea of disability but mothers were not aware of what their husband was experiencing (Seligman & Darling, 2007). It was advocated that partners had different reactions toward the situation of their children (Vural, 2010). Mine highlighted how she realized that her husband was sharing the same emotions with her as follows:

> At the beginning, I supposed that he felt shame from our children and he did not accept them. In time, we stopped being partners and we became friends. I realized that my husband was crying secretly like a child when our daughters became ill. When our daughters tried to walk, he was sweating because girls' having difficulty in walking hurt my husband so much. I realized them later… Before, he did not tell anyone that he had disabled children but now he expressed it openly…(Mine, G.122)

It might be the reason why mothers feel alone in rearing their children with disability, although fathers also experienced parenting stress. Moreover, experiencing different stressors toward the same trauma might make difficult for partners to support each other.

Neglecting Other Children at Home

In this study, except one mother, all mothers had another typically developing child. However, during the interview, none of the mothers talked about the difficulty of situation for the siblings. Mothers wanted their children to accept the sibling with disability and did not question why they experience this difficulty. Most mothers wanted their other children not to create any problem and did not demand anything because mothers’ lives were difficult enough. When siblings did not tolerate their other children with disability, they forgot that these siblings were also children who had some emotional, instrumental and social needs. Because mothers expected their non-disabled children to behave maturely and understand why their sibling with disability came first. In longitudinal study conducted by Weisner (1993), equal treatment of children which consisted of allocating time, money and activities equitably to each child was the prominent idea (Koch& Mayes, 2012). But in our study, prioritizing the child with disability was the general tendency and some mothers refused the needs of their other children in childhood. On the other hand, it was the right of sibling to express his or her needs, assert their rights and be treated as other children (Burke, 2003). But in this way, with the intention of not to neglect the child with disability, they neglect the typically developing child. Melike told her opinions as follows:

> I wish I did not have my older daughter so that I would only take care of Burcu. But now my older child had problems, too. If I had a chance, I would

> not have another child. I could devote my all attention to Burcu. It is very difficult, I cannot deal with my daughters. (Melike, G.123)

Stigmatization

Throughout the interview, mothers emphasized the inequality their children experienced in society due to their disability. Because they were labelled as "abnormal", other others did not want their children to play or talk with them. Teachers did not want the children with disability to be included in their class. Teachers labeled these children as "stupid or handicapped" and could not understand why these children were placed in inclusive setting as it was also discussed by Seligman and Darling (2007). This result was contradictory to those of Rakap and Kaczmarek (2010) who found out that teachers in Turkey had favorable attitudes toward the inclusion of students with disabilities. For example, Aylin stated that although her son with disability did not have inappropriate behavior among peer groups, he was accused of doing any mistake although it belonged to another child. She also added "Because Utku has disability, when he sits near a child, other parents tell teacher. I understand. Then this child changes his or her place in class which makes me sad. I think that they are both children; I cannot understand what their differences are." (G.124) The child was exposed to this accusing due to just his disability which reflected discrimination in our society toward disability. In my opinion, these practices show how children with disability are not accepted and discriminated from society.

In addition to this disadvantage, mothers also highlighted that their children's behavior problems could not be tolerated because their disability was not visible. Mothers thought that people had more tolerance and acceptance toward children whose disability could be seen outside or visible such as visual or physical disabilities. When they understood that the children had disability, they changed their negative attitudes or complaints. On the other hand, children with intellectual disability was difficult to understand from outside look, so they reacted these children more negatively which was also discussed by Seligman and Darling (2007). Selma discussed this issue and said “People act more tolerantly toward people with physical disability. But they are not aware of children with intellectual disability which is not understandable from outside.” (G.125)

Difficulty in Using Legal Rights

Moreover, mothers discussed about lack of opportunity given for people with disability to use their legal educational rights. Selma stated that she was not sorry for the situation of her son but she was sorry for not being able to achieve her educational goals for her son. She described herself as a parent behind closed doors and complained about not using the legal rights of her son to get proper education and therapy for his development. Special education was not enough for the benefit of children with disability and mothers also mentioned that there were lots of legal procedures which hindered the progress to development of children. In order to have a medical report, they should have contacted different places such as child psychiatry department, research and guidance center and they had to explain their problem in detail. Because these procedures were difficult, complicated and taking longer time, most mothers gave up their struggling and lost their hope from educational services. Selma said “Legal procedures stopped us. Procedures make our children regress, not progress. This is the only thing I feel sorry” (G.126). It might be related with maternal education level. Our mothers had generally primary to high school degree, so they might have experienced difficulty in following the legal procedures. Even for most mothers, it was the first time to talk with a professional to explain their problem regarding their children.

Spirituality

Interviews with mothers demonstrated that religiosity was a very powerful coping mechanism which was not covered in our literature before interviews. When mothers talked about the situation of their children, they generally did not question why this happened to them and talked about their religious faith. They thought that no one was responsible for this situation. They believed that it was a kind of test and if they could be patient, they would get a reward. They believed that this world was a temporary place in which people were tested. During the interview, they mentioned about their praying, religious practices and they used expressions such as “God knows, God will give its reward, thanks to God”. Their faith gave them interpretative framework to understand and view the disability of their children from more positive perspectives. Because they needed a meaning and reason, trusting in God provided relief and reduced their stress as it was also highlighted by Stainton and Besser (1998). Also, according to Parker et al. (2011), in time of need, religion provided comfort, patience and strengths for caregivers of children with disabilities. Necla explained this faith as follows:

> I took power from my spirituality. Because God is our creator, I take refuge in him. God makes me alive supports me. I believe that everything comes from him and this is our test. We are getting help and support from God and continue our life in this way. (Necla, G.127)

It was an effective coping factor which gave mothers emotional and psychological support (Dura-Vila et al., 2010). I considered that their psychological endurance and patience in despite of lack of support may come from their religiosity and belief in God.

Future Expectations

When mothers thought about future, they expressed no expectation and talked pessimistic. After the question of future expectation, Hediye said "It is a very difficult question. It is too early to think about future. Before anything else, Doğukan should recover and cool down." (G.128) They accepted the fact that their children would not be in better condition in later years, so they worried about how their children would take care of themselves after they died. Mothers' reactions about the future were parallel to the findings in other studies. Because these children were dependent on their mothers for their care, mothers were questioning about who would care their children after their death as stated by Sevim (2011). Furthermore, they wanted their children to have a job however, they were aware that their children's abilities were not enough to have a job. They were not sure of the ability of their children with disability to take care themselves which was also found out in research conducted by McConkey et al. (2008) and because of this, mothers had pessimism about future (Karadağ, 2009). These mothers both wanted their children to have a job for their survival but cannot believe that their children had ability to have a job. This situation creates ambivalent feelings in mothers as Aylin stated:

> What can I expect from the future of Utku? I feel that even if he had a job, he could not continue without support. I believe that he should always take support… I worried about the possibility of his being abused because he accepts what he is told to do. When I tell him to do something, he automatically does it without questioning. He does not have conscious and I am afraid of his being abused. I cannot imagine that he will earn money . He might work with my brother's office. But no I cannot believe it. (Aylin, G.129)

As in the example of Aylin, due to these ambivalent feelings, mothers could not expect positive things from future. Then, mothers felt depressed and worried about their death because they were not sure about future of their children after they died.

Due to this reason, they wanted to die with their children. Mine put this into words and said “I did not know what would happen to my child when I died. I believed what was written in our destiny would happen to us but my biggest desire is to die together. I wished to die not before or after my daughters.” (G.130)

Appropriate Interventions for Mothers

During the interviews, although it was not asked, most mothers mentioned that they were given “antidepressants” by their psychiatrists because of their depressed mood. But these medications made them sleep all day. Therefore, medications made it impossible to take care of their children with disability. They stated that they should have been awake to have an eye on their children. It was an important finding which showed that mothers who had negative experiences suffered from depression needed to have an alternative treatment in order to continue their caregiving role properly. Neriman expressed that “When we went to island where Ahmet’s attacks started, I became very down. Then, doctors gave me “antidepressants”. I do not want them because they made me sleep. I have crying periods for a week.” (G.131) This result was consistent with the findings of study which supported that mothers who had depressive symptoms or suffering from depression should have professional support from counseling or psychotherapy but in some cases, medications should have been prescribed as well (Bailey et al., 2007). It might be concluded that medication is not suitable for mothers of children with disability because of the daily routine of mothers and demands at home, so side effects of medication should be taken into account by professionals as well.

When mothers were talking about their lives, it was understood that they had some irrational beliefs about their families and themselves. Firstly, they thought that these mothers and their husbands had no right to be ill, or die. Parents should have been strong, healthy and psychologically endurable although they did not get any help from outside. Secondly, this situation made parents believe that they should not have been bored or complaining from the caregiver role. None of the mothers told that they were bored of this role because mothers believed that they did not have a right to be angry at their children or to the negative situation caused by their children. Thirdly, mothers felt responsible from the all of the things about the children with disability because they were the ones who could fulfill these demands. Lastly, mothers wanted their other children and their husbands behaved in dedicated ways. These irrational beliefs showed that there was a woman working, dealing with demands of their children and forgetting herself. Neriman highlighted her situation as follows:

> Due to catheter, everyone looked at Ahmet strangely. I stood up to everything but everything had a negative effect on my health. After Ahmet's disability, I undergo operations for nine times… But I always dressed up and put on make-up. When we went to hospital, our doctor told that he admired me. I got hurt but I always put a mask on my face. I am still putting on my mask… Now my health is very important. I should not die, or be ill. Now I am taking vitamins, taking care of myself. Why did I have cosmetic surgery? For Ahmet because he pays attention to beauty and he admires me very much… (Neriman, G.132)

Neriman's example reflected the irrational beliefs of mothers who are living for the benefits of their children with disability. It was also highlighted in study conducted in India by Kishore (2011) that mothers of children with disability ignored attention to their own personal, social and emotional needs over the needs of children. In context of Turkey, the picture was not different. In my opinion, mothers' neglecting their own needs might cause their experiencing burn-out in future. According to Bilgin and Gozum (2009), mothers of children with intellectual disability were more likely to have excessive stress, fatigue and depression. When they could not deal with these symptoms, mothers generally suffered from burn-out. Burn-out was described as “state of physical, emotional, and cognitive fatigue due to long-lasting, emotionally enforcing conditions” (Bilgin & Gozum, 2009). Mothers’ self-sacrificing attitudes may lead to long-term negative consequences for children with disability. But in examples of resilient mothers having children with disability, mothers did not perceive taking care of themselves as luxurious acts. They believed that they and their other family members also had needs and they were necessities (Gardner & Harmon, 2002). But these resilient mothers were from high SES and education level which might have an influence on their resources to cope.

Positive Influences of a Child with Disability

During the interviews, mothers pointed out the positive experiences of having a child with disability. They emphasized their growth in tolerance, having more optimistic view, expressing gratitude, being stronger and strengthening their religiosity. This finding was parallel to the literature which showed positive growth in families of children with disability (Stainton & Besser, 1998). In my opinion, it is very natural to gain positive attribution from having a child with disability because it starts accepting the difference and continues life with different point of view. These mothers have different routines, different struggles and also worries which make them stronger spiritually and emotionally than “ordinary people”.

Recommendations for Mothers

Data analysis showed that mothers of children with intellectual disability had different problems stemmed from caregiving a child with disability, organizing the whole family, lacking social support, educational barriers and legal procedures; and also stigma against the disability in society all of which were discussed in former sections. When these problems came up as a whole, it indicated that mothers were giving the signals of burn out. Therefore, the most important implication of this study is that problems experienced by the mothers of children with disability should be handled in order to prevent mothers from experiencing burn-out symptoms so that not only mothers but also all family members could function well.

Recommendation for Professionals

As literature stated, social support is very important for emotional endurance of mothers of children with disability. However, most mothers did not receive adequate support because their social contacts decreased due to the needs of children with disability and also negative stigma in our society in general. Therefore, one of the implications of the study is to conduct support groups of mothers which could provide social well-being, giving information, practical help, and increase social network of mothers. Informal help from mother to mother is more beneficial as stated by McConkey et al. (2008). Also, in order to fight with this negative stigma in society toward people with disability, advocacy is very important to help them use their rights.

Analysis of data showed that all mothers devoted themselves for caregiving of their children with disability and they neglected their own emotional, social and physical well-being in favor of their family functioning. But this situation would have block mothers’ ability to meet the long-term needs of their children because their social well-being would be reflected on the well-being of children with disability. Therefore, giving support for improving parents’ ability to have active social lives is very important as emphasized by Cramm and Nieboer (2012).

Husbands and siblings were the other sides which were negatively affected by having a child with disability in the family as the study findings indicated. Unfortunately, due to less interaction within the family, none of the family members helped one another although they were having the same difficulties coming from living with a family member with disability. Because of these needs, it was vital to provide family counseling instead of supporting them separately so that they could understand each other and give support according to the needs of family members.

Analysis of data revealed that mothers in this study had some irrational beliefs about themselves, their mothering and their family. Some emotional problems and their negative experiences might have resulted from these irrational beliefs. For this reason, another implication of this study is that using cognitive approaches in counseling could be more beneficial and suitable for these mothers.

Throughout the interviews, it was seen that professionals had an important role in families' accepting stage. Professionals attitudes toward disability, toward the family of children with disability, how they give information about the situation of children are very important for the family members to understand the issue. Different views of professionals, either negative or positive, have an effect on family members' perspectives toward their children and their conditions. Hence, professionals should know the experiences of a family of children with disability and how to approach them positively.

Religious beliefs were found to be the very strong coping mechanisms in mothers as the findings of the study demonstrated. Faith and religious beliefs gave mothers strength and hope to continue their struggle with their children. But health professionals did not take religious issues into account in clinical settings which was a lacking part to support mothers’ resilience in general. As Dura-Vila et. al (2010) emphasized, religion should be understood in order to increase coping mechanism of the mothers who have children with disability because it might have positive effects on mothers’ well-being. Therefore, professionals should understand the effects of cultural and religious issues’ healing while giving clinical support to these mothers.

Recommendation for Policy Makers

Despite the studies and laws which are published day by day with regard to conditions of people with disability, there are still problems, especially in getting medical and educational reports. In Turkey, in order to benefit from the services for children with disability, firstly children should be examined in a state hospital by child psychiatrists and medical committee make a decision about the diagnosis of disability. By this way, child with disability get the medical report in which the child’s disability and its disability level are stated. Then, with this medical report, parents should apply to “counseling and research center” where children take different intelligence and development tests. During these tests, according to the performance of children in fulfilling the objectives of the test, an educational report is given. By this educational report, children with disability gain a right to get free of charge special education services up till 8 sessions per month from rehabilitation centers. Also, these children have a right to use free transportation to go to rehabilitation centers. Therefore, children having both medical and educational report start education in inclusive setting and their children should be prepared an “individualized education program” according to the disability and developmental needs of the children in school. As can be seen, it is a very long and complicated process to get a report and include children into regular setting which is least restricted environment for their development. When children have a disability and get a report, they gain some legal rights but parents had difficulty in using their legal rights for educational needs of their children. Because most parents do not know how to follow these legal steps and from where they should start. For some parents, although they follow the legal procedure properly, they face some obstacles and their getting report process gets longer. Parents should know their rights, how to explain the difficulties their children experience, where they should apply when they get a problem in legal procedure. It is not easy for a mother who is still in a denial stage about her child's disability and sometimes this mother should defend her child's rights to get the report although she is not ready for hearing child's disability. Therefore, it is very worthy to make a need analysis to understand the needs of individuals with disability and also their family. After this need analysis, it could be possible to make appropriate accommodations for the family of individuals with disability.

In diagnosis process, children with disability were assessed with standardized tests and according to the level of their disability, they were provided a diagnosis. But according to DSM-5 and AAMR, the people should be evaluated in terms of their adaptive functioning and level of support they needed. In this study, all children were diagnosed with mild intellectual disability. From these children, only two of them could achieve making their self-care. But when looking at the features of mild intellectual disability, they should fulfill their own self-care needs. It showed that adaptive functioning and level of support these children needed were not taken into account in diagnosis process. Due to these reasons, in diagnosis of these children, authentic assessement in which multiple sources of testing and assessment tools are used should be provided.

Recommendations for Further Research

This research study aimed at understanding the life experiences of mothers of children with intellectual disability in using qualitative method with nine participants. It would be beneficial to work with larger sample or changing method into quantitative method in order to get a more generalizable data.

Another suggestion would be selecting participants from different socioeconomical and education level as much as possible. In this study, participants from high SES and education level could not be found. The problems they experienced or their coping styles could be different from the ones in this study.

Throughout the interview, it was observed that every family experienced disability within their family dynamics and every participant has a unique story although all participants are mothers of children with intellectual disability. In order to understand these unique stories in depth, phenomenological case studies could be designed and conducted.

While talking about family living with the children with disability, spouses and siblings' situations were reflected by mothers. With the aim of getting more comprehensive view point, further studies may take siblings and husbands in a sample and make a compression how these parties experienced their lives in the same phenomenon.

All mothers in this study had children having mild intellectual disability. Because these children had mild forms of impairment, it was easy for mothers to think about their children functioning in normal range. Further study might be conducted with mothers of children with moderate or severe levels of intellectual disability and then the dynamics could be analyzed accordingly.

Setting out from the data analysis, it could be concluded that having a child with intellectual disability changed and shaped the life of a mother in personal, social, interrelational and emotional aspects differently which was stated throughout the study.

Limitations of the Study

After the data was analyzed, some limitations were observed in this study. Firstly, the aim of the study was to understand life experiences of mothers of children with mild intellectual disability. Due to this reason, participants were determined on purposeful sampling, so that this study could represent only small percentage of mothers of children with intellectual disability. Even though, small number of participants was listed as a limitation, qualitative research study aims at understand the phenomenon in depth. Thus, findings in this study cannot be generalized to other mothers of children with intellectual disability in Turkey.

Secondly, most participants in this study were mothers whose children going to public school and rehabilitation centers in Kartal, İstanbul. Participants were generally from low to middle SES and had low to middle educational level. In this respect, they could not have represented the general population of mothers of children with intellectual disability in Turkey.

Thirdly, this research study is limited to the degree of information given by participants. Half of the participants in this study had joined the support group sessions run by me and I worked with their children at school. Due to social desirability bias, they might have answered questions in a way that would show them more socially acceptable. Therefore, their answers may not have reflected the reality.

Fourthly, participants in this study stated that they had difficulty in verbalizing their experiences which may stem from their education level. Also, it was participants’ first time to talk about their experiences with their children having disability so that they might not have known how to tell their stories as a whole. Thus, the answers may not have reflected their all experiences with their children in every aspect.

APPENDICES

APPENDIX A

The Interview Form in English

English Form of the Interview Questions

1. How was your pregnancy?

    a.What were your expectancies about your baby during your pregnancy?

    b.How did you expect your mothering role during pregnancy?

2. When and how did you first realize that your child is different?

    a. How was the diagnosis process?

    b. How did you react when you learned the diagnosis of your child?

    c. What did you know about this disability?

3. What do you think about this diagnosis now?

4. What did you do in order to learn more about the disability?

5. How is like being the mother of X? (name of the child:X)

    a. Is there any difference in your mothering between X and your other child?

6. How is your typical day with X?

    a. Did you experience any problems?

    b. What necessities being the mother of X?

7. How was your relationship with your husband before the diagnosis of X?

8. How can you describe your current relationship with your husband now?

9. What are your expectations regarding your child's future?

10. Which message would you like to give as a mother of children with special needs to other mothers?

11. How did your child's disability affect your life?

    a. Did the disability contribute to you positively?

APPENDIX B

The Interview Form in Turkish

Turkish Form of the Interview Questions

1- Nasıl bir hamilelik dönemi geçirdiniz?

    a. Hamilelikte çocuğunuzla ilgili beklentileriniz?
    b. İleride nasıl bir annelik rolünüz olacağını düşündünüz?

2- Çocuğunuzdaki farklılığı ilk ne zaman ve nasıl fark ettiniz?

    a. Teşhis süreci nasıl oldu?
    b. Teşhis size söylendiğinde ilk tepkiniz ne oldu?
    c. Bu engel hakkında neler biliyordunuz?

3- Bu teşhis hakkında şimdi ne düşünüyorsunuz?

4- Bu konuda bilgi almak için neler yaptınız?

5- X in annesi olmak nasıl bir şey?

    a. Diğer çocuğunuzla olan anneliğinizle x arasında fark var mı?

6- X ile bir gün nasıl geçiyor?

    a. Problem yaşıyor musunuz?
    b. X in annesi olmak neleri gerektiriyor?

7- Eşinizle çocuğunuzun teşhisi konmadan önce nasıl bir ilişkiniz vardı?

8- Eşinizle şu an nasıl bir ilişkiniz var?

9- X in geleceğiyle ilgili beklentileriniz nelerdir?

10- X in annesi olarak diğer annelere ne mesajı vermek istersiniz?

11- X in durumu ailenizi nasıl etkiledi?

    a. Olumlu olarak size neler kattı?

APPENDIX C

Informed Consent Form in English

Consent Form To Participate in Research

You are being asked to participate in a research study of “Life Experiences of Mothers of Children with Intellectual Disability”. This research study is designed to understand experiences of mothers having children with intellectual disability and how this disability affects their life from different aspects. The research is within the context of master thesis in Boğaziçi University, Institution of Social Sciences in Guidance and Psychological Counseling department. With the participants, their lives from their pregnancy until today will be discussed.

For data collection, there will be one face-to-face interview session which takes about an hour. At the end of data collection, there will be 15-minutes information building session about the rights of families of children with special needs. After standard qualitative data is collected, they will be analyzed by researcher Gökçe Piroğlu Akçakmak.

You are selected for this research as purposeful sampling. Participation of this study is completely voluntary. You have a right to withdraw from the research whenever you want. Also, you may choose not to answer specific questions or to stop participating at any time.

While analyzing data, your names and identifications will be kept confidential. During interviews, audio-recording will be used and data will be destroyed after data analysis. If you do not allow audio-recording, you can just inform it at the beginning of the interview. All information you share and your privacy will be kept and your names will be expressed as pseudo names.

I thank you for participating in my research.

I read all information mentioned above and I accept to participate in this study.

(Your signature below means that you voluntarily agree to participate in this research study.)

Date	Name-Surname of Participant	Signature

APPENDIX D

Informed Consent Form in Turkish

Katılımcı Bilgi Ve Onam Formu

Araştırmayı destekleyen kurum: Boğaziçi Üniversitesi Eğitim Bilimleri Bölümü

Araştırmanın adı: "Zihinsel Engelli Çocuğa Sahip Annelerin Yaşam Deneyimleri"

Proje Yürütücüsü/Araştırmacının adı: Gökçe Piroğlu Akçakmak

E-mail adresi: gokce_piroglu@yahoo.com

Telefonu: (535) 383 99 04

Araştırmanın konusu: Bu araştırmada, zihinsel yetersizlik tanısı almış çocukların annelerinin yaşam deneyimlerinin araştırılması amaçlanmıştır. Zihinsel yetersizliği olan bir çocuk annesinin hamilelik döneminden itibaren yaşadığı deneyimler, karşılaştığı zorluklar, baş etme yolları, kişiler arası ilişkileri ve gelecek ile ilgili beklentileri ele alınacaktır. Bu araştırma, Boğaziçi Üniversitesi Sosyal Bilimler Enstitüsü Rehberlik ve Psikolojik Danışmanlık Bölümünde bir tez çalışması kapsamında, Yrd. Doç. Dr. Z. Hande Sart gözetiminde yürütülecektir.

Onam: Bilgi toplama yarı yapılandırılmış ve yaklaşık bir saat sürecek görüşmede toplanacaktır. Görüşme bitiminde katılımcılara "zihinsel yetersizlik" ile ilgili bilgilendirme de yapılacaktır. Toplanan bilgiler araştırmacı Gökçe Piroğlu Akçakmak tarafından analiz edilecektir.

Bu araştırmaya katılmak tamamen isteğe bağlıdır. Katıldığınız takdirde çalışmanın herhangi bir aşamasında herhangi bir sebep göstermeden onayınızı çekmek hakkına da sahipsiniz. Çalışmadan çekilmek istediğiniz takdirde verdiğiniz bilgiler ve kayıtlar imha edilerek çalışma kapsamından çıkarılacaktır. Görüşme esnasında cevaplamaktan rahatsızlık duyduğunuz soruları yanıtlamama ya da istediğiniz kadarıyla cevap verme hakkına sahipsiniz.

Görüşme esnasında ses kaydı yapılması için izniniz alınacaktır. Eğer ses kaydına izin vermezseniz, görüşme kayıtları yazılı olarak tutulacaktır. Yapılan kayıtlar analizden sonra imha edilecektir. Paylaşacağınız bilgiler ve kimliğiniz gizli tutulacaktır.

Ben, (katılımcının adı) ...., yukarıdaki metni okudum ve katılmam istenen çalışmanın kapsamını ve amacını, gönüllü olarak üzerime düşen sorumlulukları tamamen anladım. Çalışmayla ilgili istediğim soruları sorabileceğim hakkında bilgilendirildim. Bu çalışmayı istediğim zaman ve herhangi bir neden belirtmek zorunda kalmadan bırakabileceğimi ve bıraktığım takdirde herhangi bir olumsuzluk ile karşılaşmayacağımı anladım.

Bu koşullarda söz konusu araştırmaya kendi isteğimle, hiçbir baskı ve zorlama olmaksızın katılmayı kabul ediyorum.

Formun bir örneğini aldım / almak istemiyorum (bu durumda araştırmacı bu kopyayı saklar).

Katılımcının Adı-Soyadı: ....

İmzası: .... Tarih: /………/………

APPENDIX E

Demographic Information of the Participants

Name of mother	Selma	Necla	Neriman	Melike	Mine
Age of mother	33	38	43	42	38
SES	High	Middle to high	Middle to high	Low to middle	Middle
Edu. Level	High school	Primary School	Secondary School	High school drop out	Primary school
Marital status	Married	Married	Married	Married	Married
# children in family	2	2	1	2	2
Name of child	Arda	Betül	Ahmet	Burcu	Canan
Sex of child	Male	Female	Male	Female	Female
Age of child	11	9	13	14	14
Diagnosis	ID + ADHD	ID + ADHD	ID	ID	ID
Age of child during diagnosis	2.5	7	19 days	7	1
Kinship with husband	No	No	Yes	No	No

Name of mother	Hediye	Hande	Filiz	Aylin
Age of mother	39	35	42	56
SES	Low	Middle	Middle	Middle
Edu. Level	High school	Primary School	High School	High School
Marital status	Married	Married	Single	Married but Husband Dead
# children in family	2	2	3	2
Name of child	Doğukan	Nazlı	Mert	Utku
Sex of child	Male	Female	Male	Male
Age of child	13	14	11	15
Diagnosis	ID + ADHD	ID	ID	ID
Age of child during diagnosis	7	3	9	1.5
Kinship with husband	No	Yes	No	No

*All mothers and their children were given a pseudo name in Turkish.

*ID: Intellectual Disability, ADHD: Attention Deficit Hyperactivity Disorder

APPENDIX F

INAREK Form

BOĞAZİÇİ ÜNİVERSİTESİ
İnsan Araştırmaları Kurumsal Değerlendirme Kurulu (İNAREK) Toplantı Tutanağı
2013/2

15.04.2013

Gökçe Piroğlu Akçakmak,
Boğaziçi Üniversitesi, Sosyal Bilimler Enstitüsü Rehberlik ve Psikolojik Danışmanlık Programı, 34342
Bebek, İstanbul
gokce_piroglu@yahoo.com

Sayın Araştırmacı,

"Zihinsel Engelli Çocuğa Sahip Annelerin Yaşam Deneyimleri" başlıklı projeniz ile yaptığınız Boğaziçi Üniversitesi İnsan Araştırmaları Kurumsal Değerlendirme Kurulu (İNAREK) 2013/32 kayıt numaralı başvuru 15.04.2013 tarihli ve 2013/2 sayılı kurul toplantısında incelenerek etik onay verilmesi uygun bulunmuştur.

Saygılarımızla,

Prof. Dr. Hande Çağlayan (Başkan)
Moleküler Biyoloji ve Genetik Bölümü,
Fen-Edebiyat Fakültesi, Boğaziçi Üniversitesi,
İstanbul

Yrd. Doç. Dr. Özgür Kocatürk (üye)
Biyo-Medikal Mühendisliği Enstitüsü
Boğaziçi Üniversitesi,
İstanbul

Prof. Dr. Betül Baykan-Baykal (üye)
Nöroloji Bölümü, İstanbul Tıp Fakültesi ,
İstanbul Üniversitesi,
İstanbul

Yrd. Doç. Dr. Özlem Hesapçı (üye)
İktisadi ve İdari Bilimler Fakültesi,
İşletme Bölümü, Boğaziçi Üniversitesi,
İstanbul

Yrd. Doç. Dr. Ekin Eremsoy (üye)
Psikoloji Bölümü, Doğuş Üniversitesi,
İstanbul

APPENDIX G

Participants’ Quotes in Turkish

1. Hamilelik dönemim gerçekten çok zor geçti. Yani nasıl diyeyim aile sorunlarım çok oldu… Hamileliğim normal gidiyordu. Ama 7. aya girdiğimde kardeşimi sürpriz olsun diye bana getirtti eşim. Haberim bile yoktu ve bunu ablası hiç istemedi. Ablasının onayı olmadan getirdiğimiz için çok olay yaşadık. Derya'nın gelmesiyle, kız kardeşimin gelmesiyle ben hastanelik oldum. Anne karnında Doğukan sancılanıyormuş ben bilmiyorum. Afedersiniz, benden leke geldi. Doktora gittik, beni hemen o gece hastaneye aldılar. Doğukan'ın işte kalp atışlarını, kalp ritimlerini kontrol altına aldılar. Kalp atışları çok yüksek olduğu için çocuk benim yaşadığım stresten dolayı sancılanıyormuş. (Hediye)

2. 24 yaşındaydım. İlk 3 ay çok mide bulantısı her şeyden çok tiksinerek başladı. 7 aylık da doğum yaptım. Suyum 12 saat önce geldi. Erken doğum yaptım ama sezeryanla da olmadı bebek küvezde de kalmadı. İlk kızımın çok rahatsızlığı var epilepsi hastası. Böyle nöbet geçirirken morardı, ellerini sıkardı. Hep Canan'da da onu yaşayacağım korkusu vardı bende. (Mine)

3. İşte evlendim bir ay sonra hamile kaldım. Güzel geçti, çok güzeldi yani. Böyle isteklerim oluyordu, her şeyi istiyordum ama şimdi Allah var eşim her şeyi getirdi. Böyle erik, ben o zaman poşet poşet erik yiyordum. Hatta arkadaşlar benle dalga geçiyordu, yenge ağaç doğuracak diye. Başka da sorunum yoktu. Devamlı da kontrole gidiyordum. Her şey güzel gidiyordu sorun yoktu normaldi. Hiçbir sıkıntı yoktu. (Hande)

4. O zaman 40 yaşındaydım, emekli oldum. 2 ay sonra öğrendim emekli olduğumu. Menapoza girdim diye çok önemsemedim. Doktora gitmedim. 2 aydan sonra doktora gittim, dedi hamilesin. Ben şaşırdım, şok oldum. Dedim Allahım noldu. (Aylin)

5. Hamileliğim ablası kadar zor geçmedi. Sadece ilk dört ay çok aşırı mide bulantısından pek bir şey yiyemedim. Ondan sonra yemem falan düzeldi. Bir problem filan yaşamadım ama çok ağır bir iş yapıyordum. Burcu'nun rahatsızlığını da ona şey yapıyorum. Bir araba fabrikasında dakika ile bir iş yapıyordum. Hava yastığı yapıyordum. Yetiştireceksin diye baskı yapıyorlardı. Bir de elim çabuk olduğu için o zamanlar benden seviyemin dışında, herkesten çok yaptığım için kendi işimi bitirince bir de etrafa yardım ediyordum. O derece baskı yapıyorlardı, hamilesin filan demiyorlardı. Sen yapabiliyorsun, yapacaksın… Bana çok iş yüklüyorlardı. (Melike)

6. Bir de ilk bebeğimizdi ama aman aman çok beklentimiz yoktu diğerleriyle mukayese ederekten. Hani normal diğer akranları gibi büyüyecek, kendi yolunu kendi çizecek, ne yapmak istiyorsa öyle olacak. O şekildeydi zaten. Bu tarz sürprizlerle karşılaştık. (Selma)

7. Tabi çok güzel beklentilerim vardı. En basiti bir kere onların okumalarını çok isterdim. Hani ben okulu çok seven birisi değildim. Sevseydim hiç engel yoktu.

Ailemden falan, bazı aileler okula gitmesini istemez. Benim öyle sıkıntım yoktu. Ama ben okulu kendi isteğimle bıraktım. Herhalde çocukluktan, şu anki aklım olsaydı bir meslek bir mevkii sahibi olmak isterdim. Ve ben bunu anlayamadığım için çocuklarıma anlatıp çok güzel bir gelecekleri olmasını isterdim… Büyük kızım hastaneye yattı falan diye anlatmıştım ya aslında çok farkında değildik. İkincisi ise tamamen planlı bebekti. Çağla yaşayamadıklarını onda görmek istedim. Ama Canan Çağladan daha fazla hassas oldu… Ama çok isterdim ikinci kızımın sağlıklı olmasını. (Mine)

8. Öyle hiçbir plan proje yoktu. Sadece hamileydim öyle şey yapıyordum. (Aylin)

9. Böyle olacağımı hiç tahmin etmiyordum bir kere. Çok sabırlı ve çok özverili bir anne oldum. Ve ben çok değiştim. Ben çok uçarıydım, hiç dönüp ardıma bakmayan biriydim. Mesela arabayı son gaz çekip giderim, hiç arkama dönüp bakmam. Şu an 2 kere düşünüyorum çünkü arkada 2 çocuğum var. Yani ben, ben değildim. Ben kendim olarak yaşamamayı öğrendim bir kere. Önceliğim evlatlarım oldu, evim oldu. Yani ben dehşet, 199 derece değiştim. (Mine)

10. çocuğa hasret, aç bir anneyim. Her şeyini ben yapayım çünkü hasta büyüttüm. “ben anne oldum mu?” gelecekteki kitabımın adı olacak. Anne gibi olmadım. Hani bir bakıcı oldum, bir doktoru, bir hemşiresi ama hep korktum titredim. Çok sevip doyasıya öpmedim, çok kızıp bir tane vurmadım. Dışarıdaki anneler gibi rahat hiç olmadım. Olmak isterdim açıkçası. Evimde oturup Ahmet’imi beklemek isterdim şu an, okulda değil. Onları yaşadım. (Neriman)

11. Doğukan karnımda acayip dönüyordu. Böyle çok hareketli, tabiri caizse sanki yılan var gibi. Böyle dolaşıyor yani. Benim ilk hamileliğim olduğu için ben bunu anlayamadım… Ama işte ondan bir hafta sonra olaylarım başladı. Hastaneye yattım, araştırma devlet hastanesine Kartal’a. 7 ün orada prepar iğne adı altında tedavi uyguladılar. O işte çocuğun kalp ritimlerini normale çeviren iğneymiş. (Hediye)

12. Ama doktora gittiğim zaman Betül 4 aylıkken gitmiştim, kafasında su baloncukları olduğunu söylemişti doktorum. Çok üzülmüştüm o zaman ama bunun önemsiz, geçebileceğini aslında şu anda normal bir hamilelik döneminde, kaçıncı hafta olduğunu hatırlamıyorum şimdi, geçmesi lazım dedi. ama bazı hamileliklerde de geç geçiyor dedi baloncuklar. Onun için 2 ay sonra tekrar çağırdı. Gittiğimizde geçmiş dedi, düzelmiş dedi ama o benim içimde hep bir ukde olarak kaldı yani. Peki geçmezse ne olur demiştim. Çocuğunuz sakat olabilir demişti o zaman. İşte o benim içimde hep kaldı yani. (Necla)

13. Sadece Arda’yı normal doğum yapmak için çok bekledim. 2 gün bekledim. Suyum bitmişti doğum esnasında. 8 saat suni sancı çektim suyumun bitmesine rağmen 2 gün öncesinden. Daha sonrasında susuzda normal doğum gerçekleşmeyeceği için sezeryana alınmıştım. Son dönemine kadar her şey çok iyiydi. O anda öyle bir şey yaşadım. Hatta hep ona bağlarım işte susuz kaldım, çok

bekledi, normal doğum olsun diye çok bekledik. Sonra susuz bir sezeryana alınmamdan belki bu rahatsızlığı kaynaklanmıştır diye düşünüyorum. (Selma)

14. Doğumdan sonra down sendromlu mongol dediler. Şüphelendiler yani tam değil ama şüphelendik dediler. Marmara hastanesi, Cerrahpaşa'ya gittik. İşte Cerrahpaşa'da gerçek sonucu öğrendik. İşte Down sendromlu, yaşıtlarından geri, yaşıtlarına göre biraz geri takip edecek. (Aylin)

15. 7 aylıkken beyin kanaması geçirdi. İlk kanamasında anlamadılar. Israrla kafasında problem olduğunu söyleyince araştırmaya aldılar ama bir hafta içinde ikinci kanamayı geçirince artık öldü deyip bakmadılar. Hatta eşim doktorun birini dövmeye çalıştı… Ameliyatını ettirdik zaten ameliyatta şey istediler ölecek, yaşarsa da sakat… 2 ay hastanede kaldık. İkinci ameliyatı oldu. Şant taktılar… Ondan sonra hastaneden çıktığımızda kesinlikle Burcu'da bir gelişme yoktu. Yani bitkisel bir hayat, konuşmuyor, kafası boynunu tartmıyor, hiçbir tepki hareket yok. İki yıl ben bunla mücadele ettim. (Melike)

16. Nazlı'nın akşamdan ateşi vardı. Kayınvalidem dedi getir bir aspirin ver ateşi var diye. O bebek aspirini içti sonra yattı. Sonra sabah kalktık ki bu bizimle yattı, bu çift kişilik çarşaf böyle kan. Ama böyle nasıl çeşme gibi burnundan. Biz apar topar acile götürdük… Nazlı o zaman 3 yaşında. Sonra işte tahlil yapıldı. Vücudunda beyaz ünite denilen kan hiçbir şey kalmamış. Ta Çapa'dan kanı geldi. İşte hemen hemen 1 ay yattı. Kanı falan değişti her şeyi. Bir de dalak büyümesi var dediler. İşte dediler kendini bilinceye kadar koruyacaksınız, düşmeyecek, çarpmayacak. Hani cam nasıl kırılmasın diye Nazlı da öyle… İşte hemofil dediler. (Hande)

17. İlk defa gerçek bayramımdı. Sonra Ahmet'e vitaminini verdim. Morardı, rengi değişti. Hani ışıktan dolayı florasan yanıyordu, belki ondan dolayı farklı görüyorum dedim. Birden morardı. Baba, dede camiden geldiler. Ahmet'i gördüler, rengi niye böyle dedikleri anda bütün yüzü mosmor oldu, kafa düştü. Öldü diye feryat ettik… Hastaneye gittik. Bebeğinizi kaybediyorsunuz dediler… İşte yanlış teşhis. Bu hastalığı şu an bile doktorlar tanımıyor… Metabolik bir hastalığı olduğu ortaya çıkmış, idrar kokusundan anlaşılırmış, pastırma çemen gibi kokarmış. Yani doğmadan anlaşılmazmış. (Neriman)

18. Doğduktan sonra kalp delik, down sendromlu dediler. Hastaneye gittik, 3 ay zatürreden yattık. Ondan sonra da bu iyileşmiyor kalp delik olduğu için Haseki Amerikan hastanesine sevk ettiler orada çok iyi doktorlar var diye. Orada ameliyat oldu. (Aylin)

19. Derken bir gün Canan'ın kolunda ataklar olduğunu gördüm. Hastaneye götürdük hemen acile yetiştirdik. Doktoru nöbet geçirdiğini ve Fahr sendromu hastası olduğunu, 1 yaşında tanısı kondu. Ondan sonra Almanya'dan bir iğne getirttik biz ona. Onunla nöbetlerini durdurmaya çalıştılar. Günde 60-70 kere küçük ataklarla nöbetler geçiriyordu. Ondan sonra uzun süre tedavi uygulandı. Sonradan birkaç ilaç kullanılmaya başlandı. Ama nöbetleri çok ağır oluyordu. Diyazem alıyordu,

oksijensiz kalıyordu. Beyin oksijensiz kaldığı için hastanede yatmak zorunda kalıyorduk uzun bir süreç. (Mine)

20. Doğum yaptıktan sonra Doğukan ağlamadı. Ben bunu fark ettim biliyor musunuz? Yirmi tane filan dikiş atıyor doktor bana, Doğukan'ı o sırada kucağına aldı böyle poposuna falan vuruyor, Doğukan ağlamıyor. Dedim ki doktor bey Doğukan niye ağlamıyor. Kadın dedi ben seni parçalıyorum, dikiyor, sen kendi işine baksana, sana ne dedi. Ağlar ağlamaz o çocuk dedi… Moralim bozuktu, stresten yemek yiyemiyordum. O iki gün üst üste yemek yiyemedim… Ben dirençsiz olduğum için çocuk anne karnında kendi pisliğini yutmuş o anda doğum esnasında… Ondan ağlayamamış. Ciğerlerini temizlemek için küveze koydular. (Hediye)

21. Yani ameliyatının olma zamanında hep ona yoğunlaştık, hastalığının üzerinde durduk. O oldu bitti ama Betül hep şey bir çocuktu çok hareketli değildi, çok mutlu bir çocuk değildi yani. Hani işte kalp hastası diye hep ona yorumladık yani biz aslında değil. Mesela Betül küçükken hırçın bir çocuktu. Halen de bazen hırçınlıkları vardır. Mesela çocukları döverdi sebepsiz yere… Betül sürekli agresifti. Mesela sürekli durduk yere insanların saçını çekiyordu… Davranış bozuklukları, insanlarla diyaloğu çok güzel değildi, bizimle iyiydi ama kendi yaşıtlarıyla iyi değildi. Bir de kendi yaşıtlarıyla onu hep kıyaslamaya başladım. Baktım Betül normal çocuklar gibi davranmıyor. Çünkü sebepsiz yere, hani çocuk kavga eder ama Betül sebepsiz yere yapmaya başlıyordu hırçınlıklar. (Necla)

22. Doğukan'ın hareketliliği 3 yaşındaydı. İnanılmaz hareketliliği dikkatimi çekiyordu benim. Nasıl diyeyim çocuğu kucağıma aldığımda yılan gibi akıp gidiyordu arkadan. Yani inanılmaz bir şey gerçekten. 1,5 yaşındayken bile onu yapıyordu ama 3 yaşındayken sinirlenince kafasını kaldırıp yere vuruyordu. Seri halde hareket ediyordu, masada ne varsa dağıtıyordu… Anasınıfında öğretmen de fark etti. Uyum bozukluğu yaşıyordu. 3 yaşında da yaşıyordu çünkü çocuklu ortama girdiğinde vurma kırma huyu yoktu çocuklara ama bir uyumsuzluk yapıyordu oyuna, iterek konuşuyordu. Hep bunu yapıyordu Doğukan. (Hediye)

23. Her şeyi çok ağır oldu. 5 yaşında yürüdü. Yine 5-5,5 yaşlarına doğru konuşmaya başladı. Hala daha özbakımını yapamıyor. Tuvalet alışkanlığından tut genel temizliğine kadar ben yapıyorum. Saçını toplamak, giysisini giydirmek, ayakkabısını bağlamak falan gibi. (Mine)

24. 1. Sınıfa giderken algılaması böyle geçti. Toplamayı filan yapıyor ama şeyde tereddütte kalıyor. Doğru mu yanlış mı diye. Getirip bana gösteriyor bakıyorum doğru. Bu sefer Zeynep öğretmen vardı, o dedi özel eğitime yazdır. Bire bir destek alsın. Ben kayınvalidemlere söyleyince bana kızdılar işte gerizekalı mı diye. Sonuçta çocuğun yani tamam da normal çocuklar gibi değil Nazlı. Normal derken 3 yaşındaki 4 yaşındaki çocuklarla oynuyor… Çok güzel konuşuyordu, hatta "anne baba" diyordu. Çok erken söyledi ama cümle kuramıyordu. (Hande)

25. O yaştan sonra yürümesi, konuşması hep geçti yani diğer akranlarına göre. Diğer çocuklarla mukayese ettiğimizde her şeyi farklı ilerliyordu Arda'nın. Hiç ağlayarak uyanan bir bebek değildi Arda mesela. Hiç ağlamazdı, mutlu uyanırdı. Daha sonra çok karanlık ortamda uyumayı tercih ederdi. Çok ışıklı ortamda uyuyamazdı… Çok hassas yani. Nasıl desem odasına üzeri açık mı kapalı mı kontrol için girsem üzerini örtmek için daha ilk adımımda uyanıp oturur. Öyle bir şey. Başka, bebekliğinde çok sık sallanan bir çocuktu. Kendi kendine sallanırdı… Arda çok da duygusaldı ayriyeten. O zamandan da belliydi. Ufak bir müzik olduğunda falan duygulanıyordu. Ömer diğer yeğenimiz de. İşte o oynarken, tempo tutarken müzikte, Arda kulaklarını kapatıp ağlardı. Biz de müziği kapatırdık, istemezdi. Yürümesi, oyun oynaması, bazı materyallerle bir şey yapmasını istediğimizde Ömer'in yapması, Arda'nın hemen sıkılıp yapmak istememesi farklı yönlere kayması… Oyun kurmuyordu, oyun oynamıyordu arkadaşlarıyla… Kreşte boyamaları arkadaşlarından çok farklıydı. Karalama yapardı. Dışarı taşırırdı kesinlikle boyaması gereken yerleri. Taşırarak boyardı. Oyunlara katılmazdı. Şiir ezberlemezdi. Şarkı sözleri, tempo yapamazdı (Selma)

26. Ben bunu 3- 3,5 yaşındayken fark ettim ama ben bunu hiçbir zaman anlatamadım. İnanmadılar bana, erkek çocuğu geçer düzelir. Hatta benim 2. Sınıfa kadar büyük bir mücadelem var… Anasınıfında öğretmen de bana dedi, hatta bir doktor da ayarladı ama ben bunu ne eşime ne görümceme anlatamadım. Hayır dedi doktor adı yok… Okula başlayınca Psikiyatri bölümüne gittik ama 1 saat aldı, anlayamadı kadın. Hiperaktiflik var gibi ama çocuk da küçük olduğu için hareketlilik normal dedi, bu denecek şey değil. Ben diyorum ki bakın farklı bir şey görüyorum ama anlamıyorum ne olduğunu… Ona götürmedi. Ne gönderdi ne götürdü, ta ki 1. sınıfta öğretmenle sorun ve yüz göz olana kadar. (Hediye)

27. Gerçekten sınıf öğretmenine nasıl anlattıysam baktım kadın ağlıyor. Gözleri dolmuş, ağlıyor. Tamam dedi sen elinden geleni yap, ben alacağım. Ama dedi bunu doktora götürmen lazım, eşini ikna etmen lazım. Eşimi ikna etmeye gerek yok, ben götüreceğim dedim. Ve Doğukan'ı 3 gün üst üste Çapa'ya gizli götürdüm. Eşimden gizli, o işte vardiyalı çalışıyordu. Gittik, Çapa'nın da yolunu bilmiyorum, Doğukan ile gittik dolaştık. Doğukan durmuyor. Doktorla görüştük. Bana 3 ayda rapor çıkarılacakken doktor 15 günde rapor çıkardı hayatımı anlatınca… Aldım o raporu dedim ki, hatta aynı gün Kartal'da kaç tane özel eğitim varsa gezdim. Özel eğitim de ayarladım, öğretmenini de ayarladım. Sonra eşime dedim ben bunu bunu yaptım, istiyorsan adliyeye uğra gel, hani diyor ya seni boşarım. İstiyorsan adliyeye uğra gel, ben yaptım. Zorumla özel eğitime yazdırdım. (Hediye)

28. Mental olan raporumuz biz 1. Sınıfa başlamadan tekrar anaokuluna gittik. O zaman RAM a yönlendirdiler bizi. O ara ne olduğumu anlayamadım aslında. Orası oraya yolladı, orası oraya yolladı. O hala da bende tam oturmuş değil o sistem. Çünkü Türkiye şartlarında teşhis konması ve o teşhis doğrultusunda hareket edilmesi, eğitim alması ve annenin ebeveynin bilinçlendirilmesi gibi bir şey yok bence. Ben kesinlikle onu söylüyorum. Hala da diyorum ya ben çocuğuma nasıl bir eğitim

verebilirim, çocuğuma koyulan teşhis gerçekten doğru mu ve bunun akabinde almış olduğu eğitim ona göre bir eğitim mi hala soru işaretlerim var. Ama yapılan bir şey var ve ben bu çizgide gitmek zorundayım. Yani zaten bunun dışına çıktığım zaman çocuğumla evde oturmak zorundayım. Başka yapabilecek hiçbir şeyim yok. Bu konuda çok kısıtlı her şey. (Selma)

29. Vallahi çok ağladım. Down sendromu ne anlama geliyor diye doktora sordum. Down sendromlu, mongol, hiç bilmiyordum o sözcükleri. (Aylin)

30. Farklı derken yani zaten dedim Ahmet'in raporu bu. Yani enzim eksikliği, beslenme problemi, yani zihinsel değil aslında. O hastalıktan dolayı yaşıtlarından geç ilerlediği için aslında olay bu ama onu başka türlü anlatamadıkları için… Ben o diyet hastalığının sonunu yakaladım kendimce. Diğerlerini kabul etmiyorum, atıyorum yok öyle bir şey olmaz, Allah öyle bir şey yapmaz. Çünkü çok özel verdi, çok istedik de verdi. Yani hiçbir şeyi yok bu çocuk diyet hastası, hep onu yakalıyorum. Zaten konuşmalarımdan da anlıyorsunuz hep oradan bakıyorum. Onu yapmazsam ben ayakta duramam. Benim gücüm biter, hiçbir şey yapamam Ahmet'e. (Neriman)

31. Ben biraz üzüldüm. Ama teyze vardı, o dedi ki korkma Nazlı cin gibi, senden benden akıllı. En azından dedi ihtiyacını görüyor, bir sorunu yok problemi yok. (Hande)

32. Hani bekliyordum zaten bir şey çıkacak. Ama bu şekilde değil hani zihinsel gerilik değil de öğrenme güçlüğü öğrenme geriliği gibi düşündüm. Zihinsel engelli olarak düşünmedim çünkü Arda'nın görseli çok iyi. Hani gördüğü bir şeyi unutmuyor. Gitmiş olduğumuz bir yere Arda'dan yardım isteyerek tekrar gidebilirsiniz. Unutmuyor o yönleri istikametleri unutmuyor. Size tarif edip götürebilir. Yıllar öncesinde bir yerde yapmış olduğunuz bir şeyi hatırlayıp size söyleyebiliyor. Bu tür şeyleri de var. O yüzden zihinseli pek yakıştırmadım Ardama. Ama dediğim gibi böyle bir şey konmuşsa da ne yapabilirim onu kazanmak için ne yapabilirim diye düşündüm. (Selma)

33. İşte Down sendromlu, yaşıtlarından geri, yaşıtlarına göre biraz geri takip edecek. Eğitimle dediler bazı şeyleri öğrenir. Biz o zaman anlamamıştık. Ben herhalde eğitimle bunu aşarım dedim. Tabi ondan sonra biz başladık mücadeleye. (Aylin)

34. Öğretmenine bir tek kelime söyledim. Çocuğumun hiçbir problemi yok, bilmiyorum hani mental retardasyon olduğunu. Hiçbir problemi yok, sadece kafasından darbe almasın diye uyardım. Uyarır uyarmaz sınıfta siz gözleyin, dışarda ben gözleyeyim mümkünse. Ben istemem al götür dedi özürlüler okuluna. 10 gün o sınıfın dışında ağladım… Çok ağlıyordum, o kadar çok ağlıyordum ki artık istemiyordu resmen… Ondan sonra neyse kuruma müracaat ettim. Dediler hastaneden rapor al, gel başlayalım. Ben anlattım öğretmeni öyle böyle yapıyor diye. Neyse hastaneden rapor almaya çalıştım ama ilk 2 ay eşimin sigortası yeni işe girdiği için inşaat işinde öyle, şey olmadı. Sigorta işlenmedi. O 2 ay zarfında ben Burcu ile çok mücadele ettim… Bir yıl ben evimin işini yapmıyordum, gece gündüz yine

annemde yiyip içiyorduk, yine başladık öyle yapmaya. Okumayı öğrettim buna… Raporu aldığımızda üzüldüm, ağladım tabi kolay bir şey değil. O zaman mental retardasyon ne bilmiyorsun, hiçbir şey bilmiyorsun. İlk defa başına geliyor, ne bileyim. (Melike)

35. Hiperaktiflik dikkat eksikliği yazıyordu. Ne olduğunu dedim ya az çok öğrenmiştim. Ama yine de üzüldüm. Çünkü bir damla gibi oldu o. Hastanede gidip gelecek, hafif düzeyde mental denildi. Hastaneye gidilip gelinecek, ben nasıl gidip geleceğim derdine düştüm. Ben Doğukan'a üzülemedim. Ben bir daha nasıl geleceğim dedim çünkü süreklilik gerektiren bir şey. Eve gelip kocama nasıl anlatacağım, ben hep onları düşündüm o anda biliyor musunuz? Ha Doğukan'a üzüldüm, üzülmedim değil neden bu duruma düştü diye. (Hediye)

36. Acayip derecede psikolojim bozuldu. Hep onları kaybedeceğim korkusu oldu. (Mine)

37. Mentali özel eğitim öğretmenimizden öğrendim. Ama hiperaktiviteyi televizyondan dinliyordum, aşırı bir hareketlilik, davranış bozukluğuyla gelen aşırı hareketlilik, bir şeye kendini verememe dikkat eksikliği gibi onları biliyordum. Ama mental retardasyona anlam verememiştim. Raporu aldım, aynı gün bulduğum öğretmene götürdüm. Dedim bana bunu açıklar mısınız. Zihin olarak, zeka olarak hafif derecede Doğukan Anlıyor musun, diyelim ki Doğukan 7 yaş, 6 yaş gibi, 5,5 yaş gibi dedi. onu öyle anlattı, öyle anladım. Ona üzüldüm ama. Anlayamadım raporu aldığımda ama öğrenince üzüldüm çünkü zeka önemli bir şey. Düzelmeyeceğini de biliyorum. (Hediye)

38. İnternetten de okudum bir şeyler. Zaten aldığı testleri de internetten arıyordum ne testi diye. Öğrendik işte. (Necla)

39. Şu an Utku ile çok mutluyum ben. Utku olmasa belki ben gülmeyi de unutacaktım. Çünkü çok sevdiğim insanları kaybettim. Utku şimdi benim hem arkadaşım, hem her şeyim oldu… Yok şimdi çok şeyi aştım. Bayağı kitap filan okuyorum. Aştım Utku ile. Tabi Utkuyla bazı olaylar yaşıyoruz. Mesela kardeşimin evine giderken onların oradaki aileler Utku'ya saldırıyor. O apartmandaki çocuklar oynuyor. Duvara bir şey yaptılar mı kim yaptı, Utku yaptı. Utku da kendini savunamıyor. Bu sefer hoş olmuyor. Utku'ya diyorum sen mi yaptın, yok diyor. Yaptığı zaman yaptım diyor. (Aylin)

40. Şimdi daha iyi, daha rahatladım yani. Daha iyiyim. Bir de şimdi biraz daha iyi, bakıyorum eskisi gibi değil Betül. Daha rahatladım bir şeyler öğrenince. Kendi başına bir yaşam kurabileceğini öğrenince daha rahatladım. Şimdi ama iyiyim. (Necla)

41. Yani ben şu 8 yılda öyle mücadeleler verdim ki, tabi Burcu günden güne iyiye gitti. 5. Sınıfa kadar teşekkür takdir alan bir insandı. Sınıfta iyiydi, özel eğitimde öğretmenleri çok iyiydi o zaman kurumda çok iyi bir öğretmeni vardı. Zaten o

gittikten sonra Burcu'da gerileme başladı. Hep tahtada yanlışları düzeltirdi yani o derece, öğretmeni hep takdir ederdi Burcu'da ilerleme var diye. Ama dersler ağırlaştıktan sonra Burcu yavaş yavaş düşmeye başladı. Ödevlerine artık karışmıyorum kendi çapında yapıyor ama doğru ama yanlış hiç karışmıyorum. Yanlışsa uyarır diyorum öğretmenleri bir şekilde. (Melike)

42. Bana bunu siz yapmadınız, herhangi biri de yapmadı… Yani onlarla yaşamaya alıştım ve diyorum ki bugün Allahıma hamd olsun ki iyi ki de öyle iki çocuğum olmuş. Ben onlarsız nefes alamıyorum, Rabbim acılarını göstermesin. Bana normal çocuklar anormal geliyor artık. O kadar alışmışım ki, hayatım o kadar onlarla özdeşleşmiş ki bilmem hiç yadırgamadım aslında. Belki de kız kardeşimin de fiziksel engeli olduğu için, ne bileyim belki de ondan hiç zorlanmadım… Ama şu anda beni en çok etkileyen kısmı nöbetleri. Hani zekaları geriymiş, fiziksel engelleri varmış, bunlardan ben hiç gocunmadım. Sadece hala nöbetlerinden de gocunmuyorum. Ama çok çaresiz kalıyorum… Bunun haricinde beni rahatsız eden veya benim çocuklarım niye böyle, işte herkese bakıyorum çocukları böyle ben böyle falan, hayır ben rahatsız olmuyorum. (Mine)

43. Şimdi hiperaktiviteymiş, mental retardasyonmuş onları düşünemiyorum. Onları aştım. Doğukan'ın şu an yaşadığı daha ağır bir şey var, çocuk psikozu. Şu anda kafam onunla meşgul. Onları bir kenara koydum çünkü onlar peynir ekmek geldi bana. Doğukan'ın şu an yaşadıkları, zaman zaman ağlama krizleri geliyor. Dün mesela özel eğitimde arabada gelirken birden ağlamaya başladı. Ama öyle içli içli ağlıyor ki Doğukan daha çocukluğunda öyle ağlamadı ya. O biraz ağır geliyor. Doğukan'ın hiperaktiflik hikaye, onlar aşılmayacak bir şey değil diyorum. (Hediye)

44. Bu çocuklar zaten kendini çok fazla ifade edemiyor. Fazla bir şey söyleyemiyorsunuz. 1 defaya mahsus 5 dakikalık veya 10 dakikalık bir görüşmede bu teşhis gerçekten doğru mu? Hala onu düşünüyorum. Buralara kadar geldik. Raporla eğitim aldı, okumaya yazma öğrendi. Sınıfta kaynaştırma öğrencisi zaten. Sınıfta bir tersliği, arkadaşlarına zararı veya uyumsuzluğu falan kesinlikle yok. Ben 1 sene boyunca Arda ile derse girdim. Ben diğer çocukların Arda'dan daha hareketli, çok çok daha yaramaz, laf dinlemez olduğunu görünce ha dedim Arda'nın hiperaktifliği yokmuş o zaman dedim kendi kendime. He tamam biraz geç öğrenme güçlüğü olabilir. Yani öğrenme güçlüğü teşhisi konabilir ama şimdi %70 zihinsel engelli teşhisimiz var raporumuzda. (Selma)

45. Keşke dedim daha erken götürebilseydim, daha erken başlasaydık eğitimine. O şekilde düşündüm tabi. (Filiz)

46. Şu an o teşhisler hakkında hiç iyi şeyler düşünmüyorum. Neden çünkü en başta çok iyi bir tarama yapılabilirdi. En baştan daha başa gideyim tüp bebek yaptırırken ben doktorumuza akraba evliliği olduğumuzu söyledim. Ben guatr hastası olduğumu söyledim… Ben doktoruma bunları söyledim. Neden söyledim çünkü korkularım var. Hani guatrım var ondan dolayı tüp bebek yapılır mı? Çünkü hormon yüksek, siz de hormon vereceksiniz, ben iyice hormon yükleneceğim. Bebekte bir problem çıkar

mı? Ve çok inanıyorum ki Rabbime, hep hissediyordum. Akraba evliliği diye belki bir problem çıkacak, eşime hep onu derdim belki Allah bizi seviyor da vermiyor, niye bu kadar isyanlısın, herkesin çocuğu olacak diye bir kaide yok. Tabi ki o öyle düşünmüyordu… Tüp bebeğe embriyolar çok iyi araştırılarak transfer edilebilirdi, çok iyi araştırılmadı. Akraba evliliğimiz göz önünde bulundurulabilirdi. Gebelikten aminosentez mi diyorlar, işte onun yapılmasını istedim, eşim istemedi. Hatta randevumu iptal etmişti, onda bile halen kızgınım… Hamilelikte dişim çekilmişti, 6 aylıktı. Ona çok üzüldüm. Doktorum izin vermişti, saçlarımı boyatmıştım. Onları sorguluyorum. (Neriman)

47. Down sendromu var dedi. Sonra Down sendromu yaşıtlarına göre geriden takip edecek dedi. Mesela sağlıklı bir çocuk hemen öğrenir, bu biraz geç öğrenir. (Aylin)

48. Doktorumuz yalnız yaşıtlarından iki- üç yıl geriden takip edebileceğini söylemişti ameliyat eden doktorumuz. (Filiz)

49. Dikkat eksikliği, unutkanlık diye yönlendirdiler beni, öyle bilgi verdiler. (Melike)

50. Doktorumuz dedi ki işte bir ilacı tedavisi çıkana kadar beynini ve tüm organlarına zarar veriyor sadece zihinsel değil. Siroz olabiliyor, böbrekler tükeniyor diyaliz olabiliyor. Her şeyi yani o yüzden diyeti güzel uygulanıp güzel eğitimini alırsa yaşıtlarını buluğ çağından sonra katlayabilir. Yani bırakın yaşıtlarını katlayabilir çünkü özel besleniyor… Mesela şu an bütün aileler çocuklarına çinko testi yaptırmıyordur. Kurşun testi yaptırmıyordur. Ama Ahmet'in her şeyi yapıldığı için neyi fazlaysa o durduruluyor, neyi eksikse çinko takviye ediliyor, öteki takviye ediliyor. (Neriman)

51. Bir yerlere başvurmadım aslında. Sizin gibi buranın öğretmenleriyle olsun, hastanede doktorlarla çok haşır neşir oldum. Bu hastalıkların neden olduğunu, nasıl yaşamam gerektiği söylendi. Daha sonra ben de bilgisayardan, internetten şimdi çağımızın teknolojisiyle araştırdığım kadar tecrübe edindim. Onlara baktım. Doktorlara sorarak, bu kadar. (Mine)

52. Down sendromunun ne olduğunu duyunca o sefer eğitimine ağırlık vermeye başladım. Artık nerden ne bulursam. Marmara hastanesine gidiyorum, oradan son sınıf öğrencilerden yardım almaya başladım… İşte sonra eğitim için İSÖM'e gittim. Orada sağ olsun Sezgin bey bize eğitim, aile eğitimini verdi. Oradan dediler sizin çocuğunuz sağlıklı çocuklar içinde durursa daha iyi olur, sosyalleşir. Bayağı yön verdi, kitap da verdi bana. Kitaplar aracılığıyla 2 senede son sınıf öğrencilerini yönlendiriyordu o zaman evlere. (Aylin)

53. Bence çok güzel bir duygu… Diğer çocuklardan çok daha bana düşkün. Ben de ona çok düşkünüm, belki ondan dolayıdır. Hep yanındayım, doğru mu yapıyorum bilmiyorum ama. Hiçbir sıkıntımız yok. (Filiz)

54. Ahmet'in annesi olmak çok güzel bir şey. Bin defa dünyaya gelsem inan ki yine Ahmet'i isterim. Başka hiçbir çocuk istemem, ikinci çocuk istemedim tekrar tüp

bebek yapıp Ahmet'e kardeş olsun. Ama Ahmet'in ne maddiyatı ne benim sevgim bir başkasına gitmesin diye ben bölünsün istemedim. Bin defa dünyaya gelsem yine Ahmet'in annesi olurdum. İsterdim. (Neriman)

55. Valla Utku'nun annesi olmak çok güzel bir şey çünkü Utku'yu bu çevrede sevmeyen yok. Yani şu aşamada, önceki aşamalarım farklı, çok şeyler yaşadım da. Şu durumda mesela gidiyorum "aa Utku'nun annesi" diyorlar ya da Utku bir merhaba diyor. Herkesle tanışıyor, konuşuyor. Bir müzik çalsa evde oynuyor. Beni neşelendiriyor, mutlu ediyor beni. Tabi bu bir yönü. Öbür yönü de onun yaşıtlarını görüyorum mesela, dershaneye gidiyor, farklı şeyler oluyor. O da üzüyor. Diyorum acaba bana bir şey olsa ona ne olur. O da işte üzüntülü yönü… Hem tatlı tarafı var hem acı tarafı. Büyüdükçe işte daha güçleniyor. Bu sefer ben de bazen, e tabi ben de bir insanım, karşısında bazen o kadar sağlıklı olmuyor. İnatlaşıyor bu sefer, istediğini yapmaya çalışıyor. Bu sefer pekişmesin diye kendimden ödün veriyorum. (Aylin)

56. Arda'nın annesi olmak çok güzel bir şey… Yani çok güzel Arda'yı herkes çok seviyor… Arda'nın ilk 1. Sınıfa başladığı zaman annesi olmak çok zordu. Çünkü çevreye kabullendiremiyorsunuz. Artı çocuklar çok acımasız küçük oldukları için ergenler gibi düşünemiyorlar. Pat diye her şeyi söyleyebiliyor çocuklar. Öyle bir şeyler yaşadım, o zaman çok zorluk yaşamıştım. Daha sonra Arda'nın sınıfındaki arkadaşların aileleriyle tanıştık. Onlarla görüşmeye başlayınca benim onlara anlatmam Arda'yı, dışarı çıktığımızda bizi bekleyen zorluklar sorunlar ve çevredeki insanların Arda'nın fiziksel bedensel hiçbir şeyi yok, dışarıdan gayet normal bir çocukmuş gibi gözüküyor. Gayet normal çocuktan beklenilen ondan da bekleniyor. Fakat farklı hareketlerde bulunduğunda bazen Arda çok bağırarak ses çıkartabiliyor, dışarıda bir yemekteyseniz ya da alışveriş merkezindeyseniz bütün gözler size çevrilebiliyor. O bakışlar sizde olmasa bile bütün bakışları siz üzerinizdeymiş gibi hissediyorsunuz onun yapmış olduğu hareketlerden davranışlardan dolayı. Ama dediğim gibi ben sınıftaki velilerle, diğer arkadaşlarla görüşüp anlattığım zaman onların hiç bilmediklerini fark ettim… Yani fiziksel engelli diye bedensel engeli varsa biraz daha ılımlı yaklaşıyorlar, toleranslı davranıyorlar. Bir de hiçbir engeli gözükmeyen, zihninde beyninde olan çocukları fark etmiyorlar… Bu bir rahatlama oldu benim için, o zorlukları da aştım. Başka bir şey yok, Ardamla mutluyum ben yani. Benim üzerimde bir ağırlık yok ama bazen şöyle düşünüyorum; Arda'nın da diğer çocuklar gibi hakları var. Hani o da bir parkta arkadaşlarıyla oynayabilmeli, bir yerlere gittiğinde rahat hareket edip dolaşabilmeli, hani bazen sadece onu düşünüyorum. (Selma)

57. Ne bileyim bir kere öyle bir evladım olduğu için çok mutluyum. Canan çok duygusal, merhametli bir çocuk. Ondan sonra ne bileyim hassas, çok öfkelenir ama bir anda da düzelir. Keşke çok sağlıklı bir çocuk olup herkese örnek birisi olsaymış. Çok duygusal, birini sevdiğinde sonsuz seviyor bir kere. Ben onun o sevgisine saygı duyuyorum. Çok güzel bir şey. Her insan evladının yapamayacağı kadar güzel bir şey bence. Ve bu beni mutlu ediyor, gururlandırıyor da… Ya olur tabi ama o kadar az ciddiye alan var ki Canan'ı. Beni en çok rahatsız eden kısmı bu. Hani bazı

insanların alay ederek baktığını, onu önemsemediklerini gördüğümde çok buruluyorum açıkçası. Keşke herkes kimsenin sonsuza kadar sağlıklı yaşayıp, küt diye sağlıklı gitmeyeceklerini bilseler. Hiç kimse bunun bilincinde değil maalesef. Onun için de örnek olamıyor. Herkes onun kadar saf ve güzel sevmiyor. (Mine)

58. Yani ilk zamanlar zordu…Beceremiyordu. Ama şu ergenlik döneminde biraz sıkıntımız var ama yine de şikayetçi değilim. (Melike)

59. Her açıdan zor… Yani zor bir çocuktu. Hem sağlık yönünden hala da zorluyor beni. Çünkü kalp problemi de var. Hala da devam ediyor… Yani hem ondan zor yani okul ve öğretim açısından da zor. (Necla)

60. Mert'i daha çok koruyup kolluyorum. Farkındayım yani. Diğerleri de biliyor zaten… Sanki ona her an bir şey olacakmış gibi, öyle hissediyorum. Olmayacak belki ama işte annelik içgüdüsü. (Filiz)

61. Diğer kızım da var ama Nazlı'nın sevgisi bizde başka… Şimdi gelir oturur yanıma, ben bebek gibi oynarım onunla, severim. (Hande)

62. Başlarda büyük kızımı dışladım. Bütün yoğunluğum öbürüneydi. Hatta dövdüm bile. Şimdi çok yalvarıyorum, özür diliyorum, hakkını helal et diyorum, ben nasıl yapmışım diyorum. Bilmiyorum hatta yeri geliyor ağlıyorum… İkisini de ayırmıyorum şimdi. Şimdi yani bilinçliyim. (Melike)

63. Asaf çok başarılı bir çocuk. Okula gitmediği halde kendi kendine okumayı söken bir çocuk. Ben Asaf'a abisinin farklı özelliklere sahip olduğunu anlatamadım… Ben de işte abim niye böyle yapıyor, abim niye çıldırıyor niye etrafı dağıtıyor dediğinde bir türlü anlatamamıştım ona… Mesela abisiyle 1. Sınıf soru bankasını yapıyoruz ama Arda 3. Sınıfa gidiyor. Anne abim 3. Sınıfa gidiyor ama bu kitaplar 1. Sınıf kitabı demeye başladı. O zaman çok şey olmuştum yani çok kötüydü… İşte pedagog Deniz hanıma geldik ondan yardım istedik. 2 aylık bir sürede Asaf ile yüz yüze görüştüler. Fakat Asaf daha buraya gelmek istemediğini söyledi. Artık niye gelmek istemedi bilemiyorum… Ama Deniz hanımla görüşmelerinden sonra daha ılımlı yaklaşmaya başladı abisine. Abisinin yanlışlarını düzeltmeye, onu ikaz etmeye falan başladı. Çünkü önceden öyle yapmıyordu. Abiyi yok sayıyordu evde. Abiyi işte çok yaramaz, bağıran, çok konuşan bir abi olarak görüyordu… Şimdi abisinin farklı bir abi olduğunu anlamaya başladı. (Selma)

64. Ona farklı davranıyorum, Selin'e farklı davranıyorum çünkü bir tanesi sanki dünyayla bağlarını koparmış, bana muhtaç, bir şeyler öğrenmeye çalışan, bir şeyleri anlatmamı isteyen bir çocuk. Ona o şekilde davranıyorum. Kızımın dünya görüşü çok farklı nasıl anlatayım mesela benim arkadaşım gibi. Hatta benden daha ileri düşünceleri var. Onunla da iletişimimiz çok farklı. Ama annelik olarak derseniz aynı. (Hediye)

65. Yani diyorum ki çocuk büyütmek Ali olduktan sonra çok kolaymış. Gerçekten onu her zaman söylüyorum, böyle olsa daha kaç tane yapardım. Çok kolaymış meğerse. Anlatamam size. (Necla)

66. Çok fark var, dehşet var. Saymakla anlatmakla bitmez… Bir kere insanların ellerindeki velinimetlere nankörlük yaptığını yakaladım. Yani ne bileyim hiç örnek almadıklarını yakaladım. Ellerindekilere şükretmediklerini gördüm… Çocuğu normal bir ateşleniyor, ayy ölüyorlar, bitiyorlar… Ya görmüyor musunuz ben sizin için canlı bir örneğim, benim 8 ay iki kirpiğim bir araya gelmeden kızıma, dedim ya Almanya'dan bir iğne getirdi tedavi verildi. Bu bildiğiniz hormon verildi beyine. O ağır çalışan beyni güçlendirmek adına beyne hormon verildi. Ve bu dehşet derecede ödem yaptı. O ödemde vücutta sızlama yapan bir rahatsızlık iyi kötü bilginiz vardır. Ondan sonra çocuk uyuyamıyordu, beyin uyumuyordu. Ve 8 ay iki kirpiğim bir araya gelmeden ben onunla zaman geçirdim. Yoktu böyle bir şey, 35 kiloya kadar düştüm. Uykusuzluktan sinir sistemlerim çöktü. Ama bir kere yat artık evladım demedim. Diyemedim çünkü onun onu isteyerek yaşamadığının bilincine vardım. Ve çok zor bir dönemdi. Şimdi ay sabaha kadar uyumadı, sütü niye emmiyor, ay psikolojim bozuk, ya Allah'tan daha ne istiyorsun sağlıklı evladın var. Bir dönem sonra normale dönecek. Çocuk 2 yaşına geldin mi derdini anlatacak, altından bezi çıkacak. Ne bileyim ihtiyaçlarını söyleyecek. Daha ne istiyorsun? 5 yaşına kadar Canan'ın afedersiniz altını ben temizliyordum. Bizi anlamıyorlar yani. Bizi bizim gibilerden de anlamayan var aynı zamanda… Ben onların çocuklarına hassas davranırken onların tahammülsüzlüklerini görüyorum. En baş örneği sende var. Sen bana yaparsan, ben sana yaparsam bizi kim anlar? (Mine)

67. Kıyafet olayında bile kavga ediyoruz Bir de saç olayımız var bizim hep kavga ederiz. Toplamaz, hiç toplamaz. Geliyor buralara, buralara gelince de daha tüylenme oluyor. Diyorum olmaz böyle alnın hiç kalmadı zaten permatikle ameliyat olduğu zaman buralarına kadar kazıdılar. Yani problemimiz yok. (Melike)

68. Nazlı ile bir günümüz çok güzel geçiyor… Sorun yaşamıyorum da diyorum Nazlı bugün biraz odanı topla. Sonra toplarım diyor, ben de sinirleniyorum. Ben istiyorum ki ben istemeden, söylemeden kendi yapsın. Odasını toplasın. Ama yapıyor. Mesela koyup gitsem geliyorum her tarafı silmiş, süpürmüş, toplamış. Bir de kardeşine diyor gel saklanalım anneme sürpriz yapalım. Yoksa Nazlı'dan şikayetim yok. (Hande)

69. Mesela Betül kızım yabancı kişilerle konuşma diyorum. Onun bilincinde çok değil. Konuşabiliyor. Ondan sonra saçma sorular sorduğu oluyor bazen. Onlar işte beni zorluyor. Okulda arkadaşlarına olan davranışları zaman zaman, her zaman değil ama gerçi şu an daha iyi ama bir dönem çok çektim… Ya arkadaşının defterini karalıyor, ya yırtıyor onla oynamıyorlarsa. Ali benimle oynamadı diyor, ben de yırttı. Kızım bunun karşılığı bu değil diyorum yapmaman gerek. Durduk yere takıldığı da çok oluyor yani. Bunlar beni çok yıpratıyor, çok yoruyor. Okuldan şikayet alacağım diye çok korkuyorum yani… Tabi büyüdü, artık bazı şeylerin o da farkında. Rahatım yani, şimdi seviyorum onunla vakit geçirmeyi. (Necla)

70. Problem inat. İnatçılığı bayağı var. Mesela istediği olacak, istediği olmayınca inatlaşıyor… Bazen bazı kendini bilmez insanlar çıkıyor. Utku'yu kızdırıyorlar. Kızdırmasalar çok iyi. Herhangi bir problem olmuyor. (Aylin)

71. Bazen sinirli, agresif olursa hiç çıkmadığımız oluyor çünkü güvenemiyorum. Yolda kaçma huyu oluyor, arabaların önüne gidiyor. Ağlıyor, bağırıyor, sanki o anda beni tanımıyor. Ben onlardan artık çekiniyorum. (Hediye)

72. Çok memnuniyetsizlikleriyle karşılaşıyorum. Çok sıkılıyorlar, hep bir yerlere gitmek istiyorlar. Sokakta bir market gezmek istiyor, bir sinema, tiyatro dışarı sosyallik isterken diğeri de ev oturmasına. Çünkü konuşmayı ve oynamayı sevdiği için 2 zıt tercihte bulunuyorlar. Evde bunun kapışmasını çok yaşıyorum. Biri pasta istiyor, birisi ne bileyim kurabiye istiyor. Hadi bakalım onunkini yapsam o huysuzluk yapıyor, onunkini yapsam o huysuzluk yapıyor. İkisini aynı anda yaptığımda ben bitiyorum. Yani benim hayatım çok sıradan değil aslında. Çok yorgun ve işte o yüzden beynim artık iflas etti. Yorgun, çok yorgunum yani öyle böyle değil… Yani sorumluluğun % 100 ya o %95 i benim üzerimde… Destek veren hiç kimse yok… Kendimden, inanın kendimden besleniyorum. Herhangi hiçbir şeyden beslenmiyorum… Hayatımın en büyük destekçi 2 çok önemli insanını kaybettim ve 1 yılın içerisinde… Bir kere büyük kızımın yükünü tamamen anneanne alıyordu. Annem mesela kızımı alırdı tatile götürürdü. Günlük dışarı çıkılacak büyük kızımın sosyal hayatını annem karşılardı. Benim evde daraldığım zaman, çok dolduğum zaman, biriyle bir şey paylaşacağım zaman da arkadaşımdı Yeşim dediğim abimin eşi. O da öyle yükümü hafifletiyordu. Yani benim için biri sağ, biri sol kolumdu. Ve bir anda ikisi de 10 günün içinde gittiler. Bu bana çok felaket ağır geldi. (Mine)

73. İlk başlarda yaşamıştım 1.sınıfta. ödevlerimiz oluyordu çünkü. Bunu yapman lazım şöyle yapman lazım, işte dişlerini fırçalaman lazım, elini yüzünü yıkaman lazım, kıyafetlerini kendin değiştirip çantanı kendin hazırlaman lazım. İlk .1sınıftaydı bunlar. Hepsinden bunalmıştık, çok şey yaparak olmuştu. Artık 2 senedir tamamen her şey rölantide gidiyor. Yani ben çıkarıyorum onun üzerini, ben fırçalıyorum dişlerini, ben giydiriyorum. Çantasını beraberce yapıyoruz çünkü tek başına onları yapamıyor demek ki diyorum. Yapabilse, her gün aynı şeyleri yapıyoruz, her gün ikaz ediyorum yapması için. Yapabilse, yapabilecek yapıda olsa yapar. Ama yapamıyor. Demek ki kendine hükmedemiyor diyorum. Demek ki yapamıyor diyorum ve onunla beraber yapıyorum. (Selma)

74. Ahmet'in annesinin Ahmet'in hayatını yaşaması gerekiyor. Özel bir hayat kendine istersen olmuyor çünkü Ahmet ihmal ediliyor. Sadece Ahmet ile her şeyi düşüneceksin. Bütün programın Ahmet olacak. Her şeyin Ahmet olacak. Sadece Ahmet'in annesi olacaksın. Onun yanında eş, arkadaş, birçok şey olmaya çalışırsan Ahmet'i ihmal etmiş olursun. Ama ben bu arada hepsini yapmaya çalışıyorum. (Neriman)

75. Arda'nın annesi olarak cep telefonunuzu yanından ayırmıyorsunuz, okuldan her an haber gelebilir. Hani altına kaçırmış olabilir, yemek yerken üzerini kirletmiş olabilir, her an öğretmeni arayabilir. Çok uzun süreli bir yerlere gidemezsiniz, gittiğiniz zaman okul çıkışı evde olmanız gerekiyor. Eve gelecek çünkü ihtiyaçları var. Eğitime gelmesi gerekiyor, baba bırakıyor ben buradan gelip alıyorum. Yani diğer anneler, diğer veliler gibi çocuğu okula bırakıp istediğiniz yere gidemiyorsunuz. Saatlerce bir yere gidemiyorsunuz. Veya arkadaşınızı arayıp işte siz bize gelin diye misafir çok davet edemezsiniz. Çünkü evde çok hareketli ve döküntülü. Birisi geldiği zaman sizin yanınızdan hiç ayrılmayan, sürekli sorular soran bir çocuk. Bir alışverişe gittiğiniz zaman hemen her şeyi alıp halledip dönmeniz lazım. Çünkü orada sıkılıyor, sizin yanınızda dolaşmıyor… Rahat işte alışverişim bitti, şurada oturup bir kahve içeyim diyemezsiniz. Çünkü sıkılır oralardan ve eve gelmek ister… Arda'nızı hiç yanınızdan ayırmıyorsunuz. Kimseye de emanet edemiyorsunuz, korkuyorsunuz. (Selma)

76. Biraz daha dikkatli olmamı gerektiriyor… Mesela kafasına top değmemeli, kafasına sert darbe almaması lazım. Belki de ben bu yüzden daha çok üzerine titriyorumdur. Zarar görmemesi için. (Filiz)

77. Büyük kızım olmasaydı tek keşke Burcu ile ilgilenseydim. Ama büyük kızımın da sorunları var şu an. Şimdiki aklım olsa bir çocukla kalırdım yani. Bütün ilgimi ona verirdim. Çok zor bir şey yani bir onla bir onla, yetişemiyorum. (Melike)

78. Çok sabır gerektiriyor. Ondan sonra özveri. Bilgi de gerektiriyor aslında. İlla disiplinli olmak gerekiyor Betül'ün annesi olarak çünkü Betül'ün ona ihtiyacı var biliyorum. Yani özveri ve sabır. (Necla)

79. Biraz eğitimli olmak lazım. Biraz empati kurmak lazım. Utku'nun annesi olmak, ödün vermek lazım. Onu anlamak lazım, anlamazsan bu sefer daha kötü sorunlar yaşayabilirsin. Çünkü evde kırar döker. Onu pekiştirmemek için sürekli arkadaş gibi olacaksın. (Aylin)

80. Doğukan'ın annesi olmak gücü gerektiriyor. Sabrı gerektiriyor, en çok da sabrı gerektiriyor. Çünkü hayatta en büyük sınav bence sabır. Sabrediyorum, etmiyor değilim ama insan öyle bir duruma geliyor ki artık yani hiçbir şeyi gözü görmüyor. Sabır bitiyor. Ben Doğukan'a sabrediyorum, etmiyor değilim. Ama bazen sabırsızlığım da oluyor, kızıyorum, bağırıyorum. (Hediye)

81. Bir kere çok büyük sorumluluğu gerektiriyor. Ondan sonra sabrı ve bilgili olmayı da gerektiriyor aslında. Yani çeyrek, yarım demeyeyim o çok olur ama, çeyrek doktor olmayı gerektiriyor. Onun hal hareketlerini gözlemlemem gerekiyor. Bir kere yükü çok ağır Canan çok okkalı bir çocuk, böyle boy pos yapılı bir çocuk. Onu yıkayabilmem için güçlü olmam gerekiyor en en basiti. Yani her türlü ya çok güçlü olmak gerekiyor. (Mine)

82. Doğukan daha yeni doğmuştu, kırklıydı. Ha bir de şöyle söz verdiler; hastaneden çıkınca beşik filan gitmiş artık orada kalacağız, başka açıklaması yok. Kırkı çıksın da eve geç dediler… Kendi evimize gitmeyeceğiz, burada yaşayacağız dedi. Ondan sonra işte benim bu 1,5 yıl içinde yaşadığım olayları dışardan gözlemleyen akrabalar babamlara anlatmışlar. O sıralar babam telefon etti. Sen dedi neden evinde yaşamıyorsun dedi eşime… Ondan sonra o saygısızlığı yaptıktan sonra ben kararımı verdim… Ben dedim Doğukan'ı alıp gidiyorum… Çocuğun daha kırkı yolda çıktı… Gider gitmez annemin kucağına fırlattım çocuğu biliyor musunuz? Ben dedim artık yoruldum, ben boşanmaya geldim dedim. Alın dedim buna bakıyor musunuz, gönderiyor musunuz, onda da gönlüm kalmadı benim. (Hediye)

83. Bizim evliliğimizde aşkım hayatımdan başka adımı duymazdım ben. Evlilik berbat bir haldeydi. O kadar kötüyüz yani neden o kadar kötüyüz onu da bilmiyorum hala çözemiyorum. Çünkü o kadar zor dönem yaşıyoruz ki o dönemde daha çok kenetlenmemiz gerekirken benim hem evliliği tutmam gerekiyordu hem Ahmet'i. Evlilik aslında gözümde yoktu, Ahmet'e baba tutmam gerekiyordu… Sonra işte hastaneden geldim babaya anlattım. O böyle sanki çok kaile almıyor gibiydi. Sanki çocuğu normal görüyor. Yani onda ne var gibi şey yapıyor. Gene tartıştık falan… İşe gitti. Ve ben o gün artık Ahmet'in acısı bitsin istemiştim. Yastığı aldım, ilaçları aldım, Ahmet ile uyuyacaktık biz. Çok fenaydı, yastık elimdeyken telefon çaldı. Arayan ablamdı. Eğer beni aramamış olsaydı Ahmet'i boğacaktım… Konuşunca ben daha rahatladım. Ağladım, bu sefer eşimle olanları anlattım. Sonra bir karar verdim… Evliliğimiz artık önemli değildi benim için. Onun için de öyle olacaktı… Bundan sonra dedim evlilik hiç önemli değil, sen ve ben, hasta olma ölme lüksümüz bile yok. 18 sene çok güzel bir evlilik yaşadık, biz artık Ahmet'i yaşayacağız… Ben seni şu an gözden çıkarabilirim, benim için bittin dedim. Ama Ahmet için bitmedin çünkü Ahmet'in babaya ihtiyacı var… Ama en zoru gitmek mi kalmak mı? Kalmak zor. Ama zoru seçmek zorundayım çünkü zor bir çocuğum vardı. Zoru seçtin tabiki ve o mücadele bu mücadele Ahmet'e çok güzel bir anne-baba olmaya çalıştık. Çok iyi bir evli olamasak bile yani bir süre olmadık. Şimdi benim için ölen birisi, peki Ahmet küçükken o kadar zordayken neden bu kadar? (Neriman)

84. Zaman zaman mesela Betül'ün problemlerinin altından kalkamayınca ben de biraz sesimi yükseltiyorum. Eski şeyimiz çok fazla yok. Ama kötü de değil iyi de değil diyeyim. Eski şeyi yok da normal. Biraz bozdu yani o söyleyebilirim rahatlıkla… Şöyle söyleyeyim, Betül beni gün içinde çok yıpratıyor. Yoruyor çünkü istediğini yaptırana kadar söylüyor. Tekrarlıyor istediğini. Anne şunu al, şunu yapalım, şuraya getir beni, gitme konusunda ya da dışarı çıkma konusunda bayağı kafamı yoruyor yani. Ondan dolayı bende de sabır falan kalmadı. Bitti. Hem onun Betül'ün hem ödevleri konusunda çok yoruluyorum. Eşimden de yardım istiyorum. O da ben şimdi uğraşamam deyince ben orada kopuyorum. (Necla)

85. Çok iyiydi ve hala da çok iyi devam ediyor. Arda'nın bizim bir gerçeğimiz olduğunu kabul ediyoruz, kabullendik. Hayatımızı ikimize göre değil de, hatta Asaf'a göre bile değil, Arda'ya odaklı yaşıyoruz. Ama bu Levent Beyle benim aramda

hiçbir problem teşkil etmiyor. Dediğim gibi anneanneye ve dedeye bırakıp bir sinemaya kaçabiliyoruz. Kendimize de vakit ayırıyoruz yani. Bazen çünkü babamızda çok bunalıyor, ben de çok bunalıyorum doğal olarak… Dediğim gibi mutluyuz çok şükür Elhamdülillah. (Selma)

86. İlk okuma yazmayı öğrenmediği zaman çok bağırıyordu bana. Hani ben de bağırıyordum Burcu'ya yeri gelince yapmıyordu çünkü bağırmayınca. Bağırıyordum yapacaksın edeceksin diye. Diyordu ya avukat mı edeceksin okumasın, bu da okumasın ne yapacaksın. Hayır diyordum ben ölürsem, o zaman epilepsi ilaçları kullanıyordu, 10 yaşında kestik biz ilaçları. Diyordum ilaçlarını almasını bilecek, hastaneye gitmesini bilecek, okuma yazma öğrenmezse bunları nasıl yapacak. Kim bakacak ona, ya hiç biriniz bakmazsanız ben öldükten sonra? Ya ablası bakmazsa? Kim bilir nasıl bir insana düşecek yani hayat şartları çok zor. O zaman çok mücadele verdim. Ödevini yapmıyordu başında duruyordum. Ama şimdi eşim gayet iyi. (Melike)

87. Hastalıklarını kabul ettik ki ben en baştan beri kabullendim. Eşim çok rahatsız oluyordu, alkole bağımlı oldu. Ben eşimden de ekstra bu iki evladım hariç eşimi idare ediyorum. Hala da aynı bazı sorunlarımız. Tabi eskiye oranla çok iyi ama eşim çok zorlandı… Alkole eğildi. Dışarı hayatı derken eve geç geliyordu, arkadaşlarıyla vakit geçiriyordu. Ondan sonra çok öfkeliydi, sinirleri çok bozuktu. Bir kere onlarla bir yere gitmeyi çok fazla şey yapmıyordu, nasıl diyeyim orayı, onlarla bir yere gitmek istemiyordu… ben ilk zamanlar eşimin çocuklardan utandığını, onları kabullenemediğini zannediyordum. Zamanla biz eşimle karı-kocalığı bıraktık, iki arkadaş olmaya karar verdik… Onlar hastalandığında çocuk gibi balkona çıkıp gizli gizli ağladığını, onlar yürürken eşimin terlerinin boşaldığını gördüm. Çünkü onların o kadar zorlanarak yürümesi eşimin canını acıtıyordu. Ve ben bunu çok geç anladım… Eşim eskiden bir yerde engelli çocuğu olduğunu söylemiyordu, şu an o kadar rahat söylüyordu ki… Hamdolsun çok iyi şu an. Eşim diyor ki sen hepimizi yönetebiliyorsun… Yani o kadar endişeleniyor ki beni kaybetme korkusu. Bana bir şey olsa çocuklar, ama bana sevgisinden ama bana saygısından. Ben yokken hep denge bozuluyor çünkü ben onların tam orta merkezindeyim. Birçok şeyi aynı anda yönetiyorum. Ahtapot gibiyim, kolum her yere yetiyor. Yetmek zorunda. Ve çok güçsüz kaldığımı anladığım için antidepresan ilaçları alıyorum. (Mine)

88. Bu çok zor bir soru Gökçe Hanım. Şu anda çok erken diye düşünüyorum. Doğukan'ın her şeyden önce kendine gelmesi gerekiyor. Sakinleşmesi gerekiyor. Gelecek için okuması tabiki isterim ama okuyamazsa da üzülmem. Çünkü kendini kurtarsın derken kendi ayakları üzerinde duracak şekilde, kişiliği oluşmuş, kimseye zarar vermeyecek şekilde, topluma zararı olmadan yaşasın, yeter bana. Ben başka bir şey istemiyorum. Üniversiteymiş, liseymiş onları düşünemiyorum. (Hediye)

89. Beklentim pek yok yani sadece işte kendini hani liseyi bitirebilirse çok çok büyük bir şey benim için. Üniversiteyi bitirmiş profesör olmuş gibi bir şey benim için yani. Öyle bir şey beklentim çok yok. İşe hani lise bitirebilirse inşallah

çalışabilmesi kendini kurtaracak kadar. Zaten başka bir şey istemiyoruz. Onların çok fazla akademik şeyleri olmaz ama bu yani biraz çalışabilmesi, iş. (Necla)

90. Yani şu an Burcu'da gelecek beklentisi bende hiç yok… Bilmiyorum, hiç bilmiyorum sanki yapamazmış gibi geliyor bana… Yani evlenip de aile yönetebilir mi hiç bilmiyorum. İş yaptığı zaman yapıyor ama bilmiyorum onu zaman gösterecek. Hiç beklentim yok yani. Ama yeri geldin mi diyorum bak yarın evleneceksin. Hatta büyüğüne diyorum kızım sen bana torun sevgisi tattırmadın. Sonra diyor anne ben tattıracağım onu sana diyor. Ne bileyim. (Melike)

91. Çok büyük endişelerim var. Annemi ve gelinimizi kaybettikten sonra olası bir durumda bana bir şey olursa ne olurlar, endişem çok büyük o konuda. Ben tek hayattaki endişem o… Rabbimden ne olur bizleri birbirimizden ayırma diyorum… Tabi olmasını istediğim sonsuz isteğim, inşallah evlatlarımın nöbetleri geçsin. En büyük, en büyük dileğim Allahımdan bu… Özel bir beklentim yok. Ama sağlıklı olmaları iyi olmaları ama evlenmeleri, işte çocuklarımın evlenmesini görmek öyle bir beklentim yok. Yok ben bazı şeyleri kalbimde dondurdum. Ne olabileceğini ne olamayacağını biliyorum. Onların da bilincinde olduğum için gereksiz hayallere kapılıp ay böyle de olsa hayatımda bu değişse demiyorum. Değişeceğini de biliyorum değişemeyeceğini de. (Mine)

92. Geleceğiyle ilgili beklentim dediğim gibi yani çok şey beklemiyorum. Fakat yapmak istediğim çok şeyler var. Çünkü eğitimle her şeyin düzelebileceğine inanıyorum. Eğitimle her şeyin aşılabileceğine inanıyorum. Sosyal faaliyetlerle bu rahatsızlıkların daha da aşağıya ineceğini düşünüyorum. Ama prosedürler gereği yapabileceğim hiçbir şey yok. sadece devlet okuluna gidiyor, burada eğitim alıyor. Gelecek için bir şeyler beklemiyorum çünkü gelecek için bir şey bekliyorsanız bir şeyler yapmak lazım. Yapamayacağınız şeyde de bir şey bekleyemezsiniz. (Selma)

93. Ahmet'ten gelecekle ilgili beklentilerim çok. Ahmet'in evleneceğini, çoluk çocuk sahibi olacağını, çalışacağını yani o kadar çok beklentiden ziyade hayalim diyeyim ben ona. İsteklerim onlar. Hani o yolda, umudum hayalim o ya, o yolda ilerlemek için mücadele ediyorum. Sonra ama toplu taşımaya falan bindiğimizde değişik hareketlerini görünce bütün gücüm, kolum kanadım kırılıyor. Hani yaşlı birisi otururken "kalkar mısınız çünkü ben oturacağım" diyebiliyor. Hani normalde hiçbir çocuk onu demez birisine falan. Onlar çok üzüyor beni. Desin istemiyorum. İşte onları da Ahmet ile konuşuyorum bunları yapma etme diye. Hani çünkü o yaşlı, senin kalıp yer vermen gerekiyor Ahmet diyorum. Hayır, ama ben oturmak istiyorum diyor. (Neriman)

94. Valla diğer annelere mesajım şu, kendi sağlıklı çocuklarının kıymetini bilsin. Çünkü çok önemli, çocuklar bizim çocuklarımız. Çünkü sağlıklı çocuklarda çok kötü davranış bozuklukları var. Yani onu şey yapsınlar, çocuklarına hor bakmasınlar. Çünkü sağlıklı, her şeyi anlıyor, her şeyi yapabilen çocuk, zeka olduktan sonra ne olacak. Ona güzel bir yön ver, iyi bir çocuk olsun, topluma yararlı olsun sana da yararlı olsun. (Aylin)

95. Ne kadar şanslılar! Yani çok benciller. O kadar bencil görüyorum ki. Hiçbir sıkıntısı yok çocuğun görüyorum mesela, hani basit bir şey için çocuklarını üzebiliyorlar. Onu bırakıp iki çene, muhabbet dedikodu yapacağım diye onun vaktinden çalabiliyorlar. Öyle üzülüyorum ki. O çocuğun o kadar sevgiye, ilgiye ihtiyacı varken anne diye çekiştiren çok çocuğu görüyorum. O muhabbete devam ediyor. Dönüp de çocuğuna bakmıyor… Veya çok sağlıklıdır çocuğu, eğitimini önemsemiyor… O kadar şanslılar o kadar… Ellerinde bir cevher var, kıymetini bilmiyorlar. Ha bu arada kendimi şansız görüyor muyum, görmüyorum. Ahmet'ten sonra kendimin başka bir hayatı oldu. (Neriman)

96. Engelli çocuğu olan annelere tavsiyem şudur, mücadeleyi bırakmasınlar. Tavsiyem budur yani. Benim kızım olmaz denilen yerden, yani buradayken buraya kadar çıktı. Bayağı ilerleme oldu. Hala da umutluyum. (Melike)

97. Yani ben çocuklarının yanında olsunlar diyorum her zaman. Çocuklarını yalnız bırakmasınlar. (Filiz)

98. Ne diyeyim herkesin başına gelen kendine göre zordur. Ama ne olursa olsun sabır gerekiyor diye düşünüyorum. Sabretmeleri gerekiyor, öyle pes edip…öyle anneler var ki çocuğu atmış, kendi derdine düşmüş, evi bırakmış gitmiş. Ben onları kabul edemiyorum biliyor musunuz? Ne olursa olsun o çocuğu bırakmamalarını söylüyorum. Başka bir şey diyemiyorum. (Hediye)

99. Bu çocuklar hepimizin çocukları. Engellisi engelsizi çocuk sonuçta. Her şeyde hakları var diye düşünüyorum. Yani irdelemenin, ikaz etmenin nasıl söylesem ortam dışı bırakmanın hiçbir anlamı yok çünkü bu dikkat dağınıklığı her yaşta olabilecek durum. Engelli olmak veya engelli annesi olmak her yaşta olabilecek bir şey. Öyle baksınlar derim olumlu baksınlar. Çocuklarını o tarz çocuklardan engellemesinler, onlarla oynayabilirler arkadaşlık kurabilirler. Bazı veliler benim çocuğum çok etkileniyor, görmesin yanına gelmesin hemen etkileniyor falan diyor. O tarz bir bakış olmaması lazım. Onların farklı özelliklere sahip birer birey olduklarını, diğer arkadaşlarıyla aynı olmadıklarını, onların da her an öyle olabileceklerini söylemeleri lazım… Herkesi her insanı olduğu gibi kabul etmek ve saygı duymak lazım çünkü hepimiz her şeyin en güzelini isteriz ve öyle bakarsak öyle görürüz diye düşünüyorum ben. (Selma)

100. Ben çocuğumu diğer normal çocuklardan düşük görmüyorum. Ben de onu, o çocuklar gibi görüyorum. Hani baktıkça diyorum benim çocuğumun hiçbir eksiği, hiçbir kusuru yok. Benim gözümde yani. Diğer taraftan algılayabilirler şöyle böyle diye ama benim öyle bir şeyim yok. (Hande)

101. Normal evlatları olan anneler her şeyden önce Allaha binlerce şükretsinler. Ben de ediyorum böyle 2 evladım olduğu halde. Yani öyle özel de bir mesajım yok. Sadece ellerindeki velinimetlerin değerini bilsinler. Ve dışarıda gördükleri bizim gibi annelere sonsuz sonsuz saygı duysunlar. Çünkü biz onların yaşadıklarının 3000, yani 1-2 katı değil demiyorum, 3000 kat daha anneyiz diyorum bence… Saygı

görmediğimizi düşünüyorum. Demin de dedim ya bazı annelerin nankör olduğunu görüyorum. Saygı görmüyorum derken de beni çok fazla anlamıyor olabiliyorlar. Bir o kadar da anlayan var. Mesela diyorlar ki ya sen nasıl bir insansın. Dün eşimin amcasının oğlu bana ya yenge dedi sen nasıl bir annesin anlamıyorum, dünyanı çocuklarının üstüne kurmuşsun dedi. Gün geldi kervan döndü, bu çocuk baba oldu. Seni şu an o kadar anlıyorum ki yenge dedi evlat bambaşkaymış. Ve dedim seninki sağlıklı, benimkiler rahatsız. Arada benim için hiçbir fark yok. 10 tane sağlıklı evlat kadar benimki de evlat… Yoksa evlat evlattır. Ama işte senin çocukların şöyle böyle diyen insanları gördüğümde bana hiç saygı göstermediklerini düşünüyorum. (Mine)

102. Ahmet'im farklı olmasın, şimdi canım çok kıymetli. Ölmemem lazım, hasta olmamam lazım. Şimdi öyle vitaminler alıyorum, kendime öyle baktığımı görseniz. Şu estetiği niye oldum? Ahmet güzelliğe çok önem veriyor, Ahmet çok çok önem veriyor. Çok beğeniyor beni… Yani Ahmet'e genç bir anne, güçlü bir anne olmak istiyorum. Uzun, sağlıklı yaşamak istiyorum. Yani Ahmet'i belli bir seviyeye getirme mücadelesi. (Neriman)

103. Utku'nun durumuyla benim arkadaşlarımla, sosyal çevremle ilişkilerim koptu. Çünkü bütün ağırlığımı Utku'ya verdim. Utku'ya bir şeyler kazandırırım, belki daha iyi olur, belki o eğitimle arayı doldururum düşüncesiyle bütün yükümü ona verdim. Çevremden koptum, uzaklaştım. Ondan sonra ilk şeyde bunu aşamadım. İnsanda özürlü çocuk olunca bazı buruklukler oluyor. Onu aşamadım ama şu anda rahatım… Ama şimdi iyiyim yani Utkuyla her yere gidiyorum. (Aylin)

104. Eşim çok üzüldü. Neden oldu her şey güzel geçti, iyi gitmişken niye konuşmuyor, niye hastalığı. (Hande)

105. Kızımı mesela olumsuz yönde çok etkiliyor. Zaman zaman onun bir günlüğü var, günlüğüne yazılar yazıyor ve ben gizli gizli okuyorum. Okutmak istemiyor ama o gittikten sonra kilitlemiyor da. Ben Selin'i çok etkiliyor diye düşünüyorum. Biz bir şekilde aşmaya çalıştık ve kabullendik. Ben şahsen kabullendim. Eşim de yine kabullenmeye çalışıyor. O da az kaldı, kabullenmedi de. Ama Selin kabullenmiş gibi gözüküyor ama kabullenmemiş. Mesela defterine o gün yazmış. Abim bir şey yaşıyor sevgili günlük diyor, sanki bizi tanımıyor, ben bunu kaldıramıyorum diyor. Abim beni tanımayacak mı? Böyle şeyler yazmış. Bunu bir hafta önce yazmıştı. Dün de şey yazmış, çok hoşuma gitti. Zannedersem o da kabullenmeye çalışıyor. Sevgili günlük diyor tamam abim hasta, annem çok üzgün ama diyor bir şeye kendi kendime söz veriyorum diyor ben de çok üzülüyorum ama sırf abim için ayakta kalacağım. Anneme destek olabilmek için, abime destek olmak için ayakta kalacağım diyor. Yıkılmak üzereyim ama zorla ayakta kalacağım dedi ben çok duygulandım, ağladım. Selin dedim günlüğüne okumama izin verir misin. Hayır dedi. Ne zaman okuyacağım dedim, hiçbir zaman dedi. Ama güzel şeyler de yazıyor bazen hoşuma gidiyor. (Hediye)

106. Hiç etkilenmedik biz, hiç etkilenmedik. Dediğim gibi ortada böyle bir şey varsa neler yapabiliriz diye düşünmeye başladık. Sadece o kadar, niye böyle oldu da öyle

böyle diye düşünmedik. Hiç etkilenmedik bu durumdan. Sadece ne yapabiliriz, nasıl faydalı olabiliriz, benim kendi ailem size nasıl yardımcı olabiliriz diye yaklaştılar. Bizim yapmamız gereken, bizim bilmemiz gereken şeyler nelerdir diye sordular bize… Benim ailem de eşimin ailesi de, hep sevgiyle bakıyoruz. Onun yapmış olduğu bazı olumsuz davranışları görmemezlikten geliyoruz. Düzeltmeye çalışıyoruz. (Selma)

107. benim Almanya'da teyzemin oğlu zihinsel engelli, konuşamıyor ve duymuyor. Bir tek o vardı bizim ailemizde. Bir tek onu bilirdik ailemizde etrafımızda engelli olarak. Bir de evlendikten sonra amcamızın yani Arda'nın amcasının bedensel engelli olduğunu gördük. Öyle gördüğümüz bildiğimiz hiç kimse yoktu. Ama Arda'nın teşhisi konduktan sonra bu tarz çocukların, bir de okula başlayınca kaynaştırma çocuklarının olduğunu sınıflarda, onların da hayatta olduklarını, etrafımızda olduklarını… mesela bir parka götürdüğüm zaman dış görünüşü normal olsa da onun bazı hareketlerde bulunduğu zaman ha diyorum bunun da bir farklılığı var. Yani bedensel gözükmese de mental engeli var. Onların da farkına varıyorsunuz. Onları görebiliyorsunuz… Daha kötülerini gördüğünüzde Arda'nın bir şeyi yokmuş diyorsunuz. Eğitimle aşılabilecek, biraz daha düzelecek bir şeyler diyorsunuz. Daha umutlanıyorsunuz diğer daha kötüleri görünce… Her şeye güzel bakıyorum, her şeye olumlu bakıyorum. Ama ben hiç kaçınmadım yani neresi varsa götürmeye gayret ediyorum. O şekilde arkadaşlar da sağ olsunlar takdir ediyorlar. Takdir edildikçe de siz daha bir umutlanıyorsunuz, daha bir şeyler yapmaya çalışıyorsunuz. Ama biri de kötü bir şey söylediği zaman hemen böyle kırılıyorsunuz, kabuğunuza çekilmek istiyorsunuz çünkü engelli velisi hele de annesi olmak gerçekten çok zor. Yani sizin zaten yükünüz ağır, herkesle cebelleşiyorsunuz, bakışlarla cebelleşiyorsunuz laflarla cebelleşiyorsunuz. Birisi de ufak bir şey söyleyince hemen yıkılıyorsunuz. Çünkü engelli velisi olmak bir tarafınızın kırık olduğu bir şey. (Selma)

108. Burcu'nun sayesinde ben çok şeyi öğrendim. Hayatla mücadeleyi, insanları tanıdım. Hastanenin içinde kimden zarar gelir, her çeşit insan tanıdım yani. Ben şimdi insan sarrafı oldum… Burcu'nun o faydası oldu. Hastane ortamını, nasıl gireceğini, çıkacağını hiç bilmezdim. Hastanelere gidince hiç konuşmazdım. Doktor soracak tek tek öyle cevap vereceğim öyle yani söylemezdim kesinlikle. Ama şimdi ilaçları biliyorum, hangi ilacın neye yaradığını biliyorum, hangi bölüme gideceğimi biliyorum, hangi hastanenin hangi doktoru iyi onu biliyorum. Çevrem çok genişledi, o konuda çok faydası oldu. (Melike)

109. Şimdi düşünüyorum da Betül için yapamayacağım hiçbir şey yok. Her şeyi yaparım. Bunun için (Ali) o kadar değil de Betül için her şeyi yaparım herhalde. Biraz sabrı kattı. Daha çok sevmeyi öğretti Betül. Şefkatli olmayı, bunlar herhalde… Kendimi gerçekten çok güçlü hissediyorum. Betül'ün böyle olması beni acizleştirmedi. İşte söylemek istediğim buydu. Şu an ağlamama bakmayın, hani ezilip onun altında kalmadım. Şimdi daha çok güçlendim. (Necla)

110. Benim eşim çok farklı bir adamdı tabiri caizse sokakta yaşayan bir adamdı… Aile düzeni yok. Yoktu ama sonra eşim aile babası oldu benim sayemde… Bir kere eşim çok daha merhametli oldu. Çocuklara çok merhametli oldu. Bir kere inancı çok güçlendi. Bir kulun Allah istemeden hiçbir şey yapamayacağını öğrendi. Çok inancı zayıf bir adamdı. Benim kızım löp diye yürüdü. Allah istemese böyle bir şey olamayacağını anladı… Bir kere ben de insan olmayı öğrendim. Şuanda bu kabaca oldu ama ben çocuk hiç sevmezdim. Şimdi inanır mısınız çingenenin çocukları dahil her çocuğu sevebiliyorum. İnsan oldum ya insan oldum bundan ötesi yok. Önceden neymişim ya delidoluymuşum. Boş bakıyormuşum ama şimdi bakan değil gören oldum. Her şeyi gözlemlemeyi öğrendim anlayabiliyorum artık her şeyi. (Mine)

111. Benim hayatımı, gönül gözümü açtı… Ama Ahmet hayatımıza, benim hayatıma çok renk kattı. Dünya çok güzel, hayat çok güzel, yaşamayı sevdirdi. Her şeyi önce baktığımın kat kat güzel görüyorum şimdi. Her sabah bahçemdeki o gülleri seviyorum ve şükrediyorum. Yani güllere, yapraklara, her şeye ince ince bakan birisi oldum. Ve her şeye bakınca şükreden birisi oldum. Onlara bakınca Rabbimden Ahmet'e şifa diliyorum… Rabbimin yanımızda olduğunu biliyorum. Ve bunun bir sınav olduğuna inanarak böyle güçlü yaşayabiliyorum. Bunun da bir gün geçeceğine ve Rabbimin mükafatını vereceğine inanıyorum. (Neriman)

112. Yani her anne-baba hamile olunca mutlu olur. Çocuğunun geleceğini düşünür. İşte şöyle olacak, böyle olacak. Okula gidecek, o tür şeyler. (Necla)

113. Ahmet'in annesinin Ahmet'in hayatını yaşaması gerekiyor. Özel bir hayat kendine istersen olmuyor çünkü Ahmet ihmal ediliyor. Sadece Ahmet ile her şeyi düşüneceksin. Bütün programın Ahmet olacak. Her şeyin Ahmet olacak. Sadece Ahmet'in annesi olacaksın. Onun yanında eş, arkadaş, birçok şey olmaya çalışırsan Ahmet'i ihmal etmiş olursun. (Neriman)

114. dışarı çıktığımızda bizi bekleyen zorluklar sorunlar ve çevredeki insanların Arda'nın fiziksel bedensel hiçbir şeyi yok, dışarıdan gayet normal bir çocukmuş gibi gözüküyor. Gayet normal çocuktan beklenilen ondan da bekleniyor. Fakat farklı hareketlerde bulunduğunda bazen Arda çok bağırarak ses çıkartabiliyor, dışarıda bir yemekteyseniz ya da alışveriş merkezindeyseniz bütün gözler size çevrilebiliyor. O bakışlar sizde olmasa bile bütün bakışları siz üzerinizdeymiş gibi hissediyorsunuz onun yapmış olduğu hareketlerden davranışlardan dolayı. (Selma)

115. İşte Down sendromlu, yaşıtlarından geri, yaşıtlarına göre biraz geri takip edecek dedi doktor. Eğitimle dediler bazı şeyleri öğrenir. Biz o zaman anlamamıştık. Ben herhalde eğitimle bunu aşarım dedim. (Aylin)

116. Ben aynı dönem içerisinde hem çok samimi olduğum arkadaşım hem abimin eşiydi aynı zamanda, onu kaybettim çok genç yaşta. Hem de aynı yıl içerisinde annemi kaybettim. Direkt böyle sönmüş balon gibi düştüm ve üstüne çocuklar ve ben yalnız kaldık. (Mine)

117. Çünkü biz onların yaşadıklarının 3000, yani 1-2 katı değil demiyorum, 3000 kat daha anneyiz diyorum bence. (Mine)

118. Betül okumayı öğrenince çok ama çok mutlu oldum. Çok iyi okuyamasa da yani kendini kurtaracak kadar bir şeyler yapıyor bakıyorum. İşte geçen yıl ders yaparken çok fazla bunalıyordum. Her şeyimi işimi gücümü bırakıp onunla uğraştım. Küçük çocuğumdan bile taviz verdim. Ama bu sene Betül derse oturma konusunda daha rahat. Yapalım diyor en azından. Önceden asla demiyordu. Ama şimdi bunları görünce rahatlıyorum, korkum daha azaldı yani. Daha çok korkuyordum. Endişelerim vardı… Şimdi de iyiyim. Belki de Betül'ün iyi olmasından çünkü şimdi gidebiliyorum her yere çok rahatlıkla Betül ile birlikte. (Necla)

119. Ahmet'in annesi olmak çok güzel bir şey. Bin defa dünyaya gelsem inan ki yine Ahmet'i isterim. Başka hiçbir çocuk istemem. (Neriman)

120. Anne gözüyle çoğu şeyi görmüyor çünkü onların günlük ilaçları benden, banyoları, ikisi de kız çocuğu, babayla akşamleyin bile evcilik oynanıyor ama bir yerden sonra " kızım az sus bakayım maç ne olmuş?" moduna giriyor. Ama ben "Canan az sus dizime bakacağım, tv ye bakacağım" öfkelendiği zaman yine ben onun peşinden gidip nazlattığım için… (Mine)

121. O hiç kabul etmedi. Ben sürekli bu çocukta bir problem var, problem var diyordum. Ailemdekileri de söyleyince işte sen abartıyorsun sen öylesin böylesin diyorlardı… O zaman eşim kendisi getirmişti işte bir şeyi yok dendi kağıt yazıldı. Mental süreci falan normal dendi. Eşim dedi bak gördün mü abartmışsın böyle söylendi. Sonra tekrardan gittik, tekrardan aynı dendi… Denver testinde de normal çıktı o testte de. Yani kolay kolay anlaşılmadı Betül. (Necla)

122. Ben ilk zamanlar eşimin çocuklardan utandığını, onları kabullenemediğini zannediyordum. Zamanla biz eşimle karı-kocalığı bıraktık, iki arkadaş olmaya karar verdik. Onlar hastalandığında çocuk gibi balkona çıkıp gizli gizli ağladığını, onlar yürürken eşimin terlerinin boşaldığını gördüm. Çünkü onların o kadar zorlanarak yürümesi eşimin canını acıtıyordu. Ve ben bunu çok geç anladım… Eşim eskiden bir yerde engelli çocuğu olduğunu söylemiyordu, şu an o kadar rahat söylüyordu ki. (Mine)

123. Büyük kızım olmasaydı tek keşke Burcu ile ilgilenseydim. Ama büyük kızımın da sorunları var şu an. Şimdiki aklım olsa bir çocukla kalırdım yani. Bütün ilgimi ona verirdim. Çok zor bir şey yani bir onla bir onla, yetişemiyorum. (Melike)

124. Mesela Utku rahatsız olduğu için çocuğu yanında otursa hemen sanki cüzzamlı olacak gibi, hemen öğretmene söylüyor. Ben anlıyorum. Hemen kaldırıyordu, tabi o bana çok üzüntü veriyordu. O da çocuk, o da çocuk ne farkı var diye kendi kendime düşünüyordum. (Aylin)

125. Yani fiziksel engelli diye bedensel engeli varsa biraz daha ılımlı yaklaşıyorlar, toleranslı davranıyorlar. Bir de hiçbir engeli gözükmeyen, zihninde beyninde olan çocukları fark etmiyorlar. (Selma)

126. Ama prosedürler sizi kapatıyor. Çocuğunuz ilerlemesin, gerilesin diyorlar yani. Sadece benim üzüldüğüm şey bu. (Selma)

127. Maneviyat. Yaradandır ona sığınıyorsun. O da seni ayakta tutan şey yani. Her şeyin ondan geldiğini, bunların bizim için imtihan olduğunu düşünüyoruz. Bir bakıma ondan da yardım alıyoruz, destek alıyoruz öyle devam ediyoruz. (Necla)

128. Bu çok zor bir soru. Şu anda çok erken diye düşünüyorum. Doğukan'ın her şeyden önce kendine gelmesi gerekiyor. Sakinleşmesi gerekiyor. (Hediye)

129. Valla Utku'nun geleceğiyle ilgili beklentim ne olabilir, geleceğinde bir meslek edinse kendi başına yapamaz gibi geliyor. Hep bir destek alması lazım, öyle sanıyorum ben… Biri tarafından kullanılır diye üzülüyorum. Çünkü hemen kabulleniyor, şu işte yap de hemen yapıyor. Git onu yap, bakıyorum hemen yapıyor, niye yapayım diye öyle bir şeyi yok. İdrak edemiyor, kullanılır diye korkuyorum. Yani onun para kazanıp getireceğini hiç düşünemiyorum. Bilmiyorum, kardeşimin iş yeri var. Belki orada öylesine bir çalışır. Hiç düşünemiyorum. (Aylin)

130. Bana bir şey olursa ne olurlar, endişem çok büyük o konuda. Ben tek hayattaki endişem o. Onun için Allaha, bilmiyorum yaradan ne yazmışsa o olur ama, en büyük dileğim Rabbimden ne olur bizleri birbirimizden ayırma diyorum. (Mine)

131. Yazları adaya gidince ilk haftaları çok kötü oluyorum. Ondan sonra hep böyle antidepresan veriyorlar. Uyutuyor, onları istemiyorum. Bir hafta böyle ağlama sürelerim oldu. (Neriman)

132. Herkes garip bakardı, sondalıydı, bilmem neydi. Herkes göğüs gererek ama her şey dirhem dirhem bir şeyler götürerek. Ondan sonra, Ahmet'ten sonra ben 9 defa ameliyat oldum. Orası ası gitti, burası gitti, yüzümden gözümden bir şeyler fırladı. Her giyindim, süslendim, böyle makyaj yaptım. Her doktora gittiğimizde hayranım size diyordu ama canım yanıyordu, hep maske taktım. Ve maskeye hala devam ediyorum… şimdi canım çok kıymetli. Ölmemem lazım, hasta olmamam lazım. Şimdi öyle vitaminler alıyorum, kendime öyle baktığımı görseniz. Şu estetiği niye oldum? Ahmet güzelliğe çok önem veriyor, Ahmet çok çok önem veriyor. Çok beğeniyor beni. (Neriman)

APPENDIX H

Mother Support Group Sessions

MOTHER SUPPORT GROUP SESSIONS

Main goal of the group

The main goal of the group sessions is to support mothers of children with different disabilities with regard to parenting skills, communicating with their children and dealing with the reality of disability in their children. This group consists of 7 sessions which take at least one hour face to face communication, some activities and practices. Mothers whose children are between the ages of 10 to 14 can participate in this group. In order to evaluate the progress and effectiveness of the support group sessions, pre-test and post-test are used.

General Goals of the Group Sessions

- to make group members informed about group sessions and how the sessions continue
- to make group members have awareness about their process of having a child with disability and their own coping mechanisms
- to make group members use the coping mechanisms of other members whose children also have disability and who also have the same experiences
- to give some information and abilities beneficial for parenting and make members use these skills to fulfill the educational and developmental needs of their children
- to provide support for the daily stress mothers of children with disability experience
- to make mothers use the information and skills they learn in the group sessions in their daily life

- to give group members the feeling that they are not alone in their struggle with their children and sense of universality

1. SESSION:

Objectives of the Session:

- making group leader and group members come together and meet
- teaching group members the rules of the group sessions
- taking group members their expectations from the sessions
- doing some icebreaking activities for making members get to know one another in non-threatening ways
- Conducting pre-test form

2.- 3. SESSION:

Objectives of the Session:

- remembering the issues discuss in last session
- making members think about the children with disabilities
- making members understand how mothers of children with disability feel
- providing safe and supportive atmosphere in which mothers tell their story with regard to learning the diagnosis of their children
- helping mothers gain awareness about the progress of their children throughout their education process
- helping mothers decide the expectations from them and their children in the future

4. SESSION:

Objectives of the Session:

- remembering the issues discuss in last session

- teaching the group members “development” and “adolescence” concepts in children with disability
- members’ gaining awareness about the difference pace of development in every child
- making mothers think of feeling children experience in adolescence period
- making mothers aware of importance of self-esteem children should gain in adolescence
- sharing the roles of parents in children’s having self-esteem
- making mothers aware of the legal rights of children with disability

5. SESSION:

Objectives of the Session:

- showing members how a communication pattern starts
- making members think about communication barriers
- helping members gain awareness about the difficulties of non-verbal communication
- teaching members how to communicate with their children having disability
- teaching members use “I” language instead of “You” language
- helping members consider about the non-verbal language they use for their children

6. SESSION:

Objectives of the Session:

- teaching members different parenting styles and their differences
- helping members gain awareness about the effects of different parenting styles on children from both negative and positive aspects

- making members understand the effectiveness of authoritative parenting styles
- making members understand the importance of setting clear boundaries in raising children, especially in children with special needs

7. SESSION:

Objectives of the Session:

- making members review the issues handled throughout the group process
- evaluating the progress in members in this 7 weeks
- conducting post-test forms
- sharing feelings and opinions about the group sessions
- giving certificates to members and making “bulletin board” of the group

APPENDIX I

Further Information about the Disorders Mentioned in This Study

Further Information about the Diseases Mentioned in This Study

Fahr Disease (FIBGC)

"Familial idiopathic basal ganglia calcification (FIBGC, formerly known as Fahr disease) is a condition characterized by abnormal deposits of calcium (calcification) in the brain. These calcium deposits typically occur in the basal ganglia, which are structures deep within the brain that help start and control movement; however, other brain regions can also be affected.

The signs and symptoms of FIBGC include movement disorders and psychiatric or behavioral difficulties. These problems begin in adulthood, usually in a person's thirties. The movement difficulties experienced by people with FIBGC include involuntary tensing of various muscles (dystonia), problems coordinating movements (ataxia), and uncontrollable movements of the limbs (choreoathetosis). Affected individuals often have seizures as well. The psychiatric and behavioral problems include difficulty concentrating, memory loss, changes in personality, a distorted view of reality (psychosis), and decline in intellectual function (dementia). An estimated 20 to 30 percent of people with FIBGC have one of these psychiatric disorders.

The severity of this condition varies among affected individuals; some people have no symptoms related to the brain calcification, whereas other people have significant movement and psychiatric problems."

Hemophilia

"Hemophilia is a bleeding disorder that slows the blood clotting process. People with this condition experience prolonged bleeding or oozing following an injury, surgery, or having a tooth pulled. In severe cases of hemophilia, continuous bleeding occurs after minor trauma or even in the absence of injury (spontaneous bleeding). Serious complications can result from bleeding into the joints, muscles, brain, or other internal organs. Milder forms of hemophilia do not necessarily involve spontaneous bleeding, and the condition may not become apparent until abnormal bleeding occurs following surgery or a serious injury.

The major types of this condition are hemophilia A (also known as classic hemophilia or factor VIII deficiency) and hemophilia B (also known as Christmas disease or factor IX deficiency). Although the two types have very similar signs and symptoms, they are caused by mutations in different genes. People with an unusual form of hemophilia B, known as hemophilia B Leyden, experience episodes of excessive bleeding in childhood but have few bleeding problems after puberty."

Hydrocephalia

"An abnormal increase in the amount of cerebrospinal fluid within the cranial cavity that is accompanied by expansion of the cerebral ventricles, enlargement of the skull and especially the forehead, and atrophy of the brain."

Maple Syrup Urine Disease (also called branched-chain ketoaciduria)

"Maple syrup urine disease is an inherited disorder in which the body is unable to process certain protein building blocks (amino acids) properly. The condition gets its name from the distinctive sweet odor of affected infants' urine. Beginning in early infancy, this condition is characterized by poor feeding, vomiting, lack of energy (lethargy), and developmental delay. If untreated, maple syrup urine disease can lead to seizures, coma, and death.

Maple syrup urine disease is often classified by its pattern of signs and symptoms. The most common and severe form of the disease is the classic type, which becomes apparent soon after birth. Variant forms of the disorder become apparent later in infancy or childhood and are typically milder, but they still involve developmental delay and other medical problems if not treated."

Source: Genetics Home Reference. (n.d.). Retrieved March, 23, 2014, from the website of Genetics Home Reference: http://ghr.nlm.nih.gov

APPENDIX J

Themes and Subthemes Emerged in This Study

1. Pregnancy
    - First Impression
    - Expectations
    - Mothering
2. Diagnosis Process
    - Perception of differences in their children
    - First reaction to diagnosis
    - Knowledge about the disability
3. Current Feelings about the Diagnosis
4. Getting ınformation about the diagnosis
5. Perception of being mother of child with intellectual disability
    - Perception of mothering of a child without disability
6. Living with a child with intellectual disability
    - Common problems in daily life
    - Requirements of being mother of child with intellectual disability
7. Relationship with their husband before diagnosis
8. Current relationship with their husband after diagnosis
9. Expectations from the future regarding their children

10. Messages to other mothers

11. Influences of a child with disability

- Contributions of having a child with disability

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