ABLEISM IN TURKEY THROUGH THE EYES OF FAMILIES WITH DISABLED CHILDREN

BURCU AYAN

114611013

Dissertation Supervisor: Doç. Dr. Itır Erhart

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SAKAT ÇOCUĞU OLAN AİLELERİN GÖZÜNDEN TÜRKİYE'DEKİ SAĞLAMCILIK

BURCU AYAN
114611013

Tez Danışmanı: Doç. Dr. Itır Erhart..

Jüri Üyesi: Prof. Dr. Kenan Çayır...

Jüri Üyesi: Yrd. Doç. Dr. Volkan Yılmaz...

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ABSTRACT

This thesis focuses on how families with disabled children experience disability in Turkey. Ableism directly affects the experience of disabled people and their families. Therefore, in this study, it is also examined how families of disabled children experience ableist society. Theoretical framework of disability is established on disability studies/ theories in the literature and changes in disability policies in Turkey. Tracing the disability studies/ policies provides a background to understand the experiences of families with disabled children in the process of raising their children. The concept of "ideal nuclear family" and the function of the child determined by the values which are related to this family concept constitute the second part of theoretical framework of this thesis. In the study, it is discussed the experiences of having a child with disabilities in reference to the findings of the research “Value of Children” by Çiğdem Kağıtçıbaşı.

The study includes a field research that conveys the narratives of seven mothers and one father, whom their children are intellectually or physically disabled. In this field research, the in-depth interviews proceeded in a semi-structured way through open-ended questions. The essential point that was investigated through the questions directed to the parents was whether there is a difference between what the parents felt/thought when their children were born and how they felt during the process of their children’s growth. The fundamental hypothesis of the thesis is that this “difference" can create the possibilities of living together in public space through the recognition and contact.

Keywords: disability, child, family, ableism, value

ÖZET

Bu tez, Türkiye'deki sakat çocuğu olan ailelerin sakatlık deneyimine odaklanır. Sağlamcılık, sakat kişileri ve ailelerinin hayatını doğrudan etkiler. Bu sebeple çalışmada ayrıca, sakat çocuğu olan ailelerin sağlamcı bir toplumu nasıl deneyimlediği araştırılmıştır. Sakatlığa dair teorik çerçeve literatürdeki sakatlık çalışmaları/ teorileri ve Türkiye'deki sakatlık politikalarının değişimi üzerine kurulur. Sakatlık çalışmalarındaki/ politikalarındaki değişimi izlemek, sakat çocuğa sahip ailelerin çocuklarını yetiştirme deneyimlerini anlamaya imkan sağlayacak bir alt yapı sağlar. Tezin teorik çerçevesinin diğer tarafında ise "ideal çekirdek aile" ve bu aileye ilişkin değerler söylemi üzerinden çocuğa biçilen işlev vardır. Çalışmada, Çiğdem Kağıtçıbaşı'nın "Çocuğun Değeri" araştırmasının bulguları yoluyla sakat çocuğa sahip olma deneyimi tartışılır.

Çalışma, çocuklarının zihinsel veya bedensel sakatlığı olan yedi anne ve bir babanın anlatılarının aktarıldığı bir saha araştırması içerir. Bu saha araştırmasındaki görüşmeler yarı-yapılandırılmış biçimde, açık uçlu sorular ve derinlemesine mülakatlar aracılığıyla ilerlemiştir. Ailelere sorulan sorular aracılığıyla araştırılmak istenen esas nokta, ailelerin çocukları ilk doğduğunda hissettikleriyle çocuklarının büyüme sürecinde hissettikleri arasında bir fark olup olmadığıdır. Çalışmanın hipotezi, bu farkın tanınma ve temas yoluyla kamusal alanda bir arada kalabilmeye dair bir imkan üretebileceğidir.

Anahtar Sözcükler: sakatlık, çocuk, aile, sağlamcılık, değer

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CHAPTER 1

INTRODUCTION

> "İnsan, kendi kendinin katilidir; düşlerini unuttuğu zaman. Mevcut toplumsal algı nedeniyle tuhafım ben. Bedensel tuhaflığım değil ama düşünsel tuhaflığım benden kaynaklıdır. Bunun nedeni ise umutlarım ve düşlerimdir. Kimi zaman ana dilini bilmediğim bir ülkede sadece beş kelime ile yaşayabilirken kendi ülkemde susturularak bir yudum su için kalem ve kağıda kelepçelendim."[1]
>
> Umut Koşan

It is important to meet. Meeting is more than playing the roles, more than biases, more than a breathless fiction. If the possible areas of meeting become narrow, if the public space becomes exclusionary, the notions I have mentioned in the previous sentence will continue to exist.

This thesis focuses on how the families with disabled children experience disability in Turkey. We have noticed that the experiences of the families did not take part in disability studies, especially in Turkey. However, the family is important, and the experience of the family with disabled child is crucial to look at how the case of disability and disabled people are dealt with in Turkey. For this

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[1] "One is one's own murderer; when dreams were forgetten. I am strange because of the current social perception. It is not my physical strangeness, but my intellectual strangeness is from me. The reason of this is my hopes and dreams. Sometimes I could live with only five words in a country where I do not know their mother tongue, but I am handcuffed in pencil and paper for a sip of water in my country."

reason, in this study, we preferred to look at the experiences of the families in the context of the ableism in Turkey and the practices it promotes.

The courage I needed to work on disability, family and intersection with society necessitated an internal feud. Aside from the difficulty that comes from the willingness to examine a wide range of notions and relationship networks, I had thought that studying this subject without having the “actual” experience of disability can be presumptuous. Then, I realized two things: first, the well-known and accepted definition of disability and disability experience itself was one of the questions asked in this research; secondly, the best thing I can handle as someone who was forced into the “normal range” was to show how the "normal" was established in a problematic way.

I must admit that this did not occur on the day when I started thinking about these relationships; rather, it was a process. The brief education about "family counseling" I took in the winter of 2016 has led me to psychologically and sociologically contemplate the bonds/relations between the family and child with regard to psychology and sociology. This effort, which corresponds to the field of cultural psychology, was the reason for rethinking the process of socialization of human being as an "individual of society" in the family context. The family to where the child is born and with which the child spent the first years is an area which is influenced by the norms and values of the society and an intermediary as the reproducer of societal norms and values. Such a view on the family may seem structural and functional in the first place, but throughout the thesis, I do not consider the family simply as a social institution or a structure that always operates with the same dynamics, rather, I focus on how the family is represented. The family is one of the main actors of governmental power relations or power politics because it leads the society to an “order”. For this reason, tracing how the disability policies in Turkey handle the families with disabled children can give a possibility for examining the representations of the family.

One of the main bearings of this thesis is the research study “Value of Child” (VOC) by Çiğdem Kağıtçıbaşı. The first “Value of Child” research took place in 1975 as a part of comprehensive field study conducted in eight different countries.

Kağıtçıbaşı's research was one of the few studies about the values and possibly the most comprehensive field research in Turkey. Details of Kağıtçıbaşı's research are discussed in the second part of the thesis, but below its importance for this study is briefly mentioned.

Çiğdem Kağıtçıbaşı established the Model of Family Change (MFC) in which the outputs of VOC research guides us to interprete the results of the research. “The model assigns a key role to the family as mediator between culture and the self. This role, through which core cultural values are handed down across generations, is not passive. Rather, the family is cast as an active agent that selectively transmits cultural values and continually adapts to changing circumstances.” (Bornstein and Güngör, 2009, p. 69) It is crucial that Kağıtçıbaşı approaches to the family in such a relationality that it is not easy to discuss the role of family in handing the cultural values down to hext generations, since the family is "naturally" present. This view of Kağıtçıbaşı allows to think the modern/core families and values though cultural norms. Besides, in accordance with the methods of cultural psychology, Kağıtçıbaşı discusses family’s view of the child by taking both motivational and social needs into account. She gathers the findings of the research under two main subjects, which are “values” and “costs” of children.

Indeed, I have examined the concept of “disability” theoretically in terms of human rights and body for a long time. The first thing I realized about disability is that otherising/ discriminating becomes "normal" when the subject matter is disability or disabled people. The body's abilities and possibilities are easily structured in a normative context when body is handled as a given substance and an integrated existence. This “certain” knowledge of body leads to the idea that “disability is an impairment itself”. This idea creates another discrimination between “fixable” and “non-fixable” impaired bodies through medicine.

Different theories and perspectives about disability is traced in the first chapter of the thesis. Below, I attempt to explain how the matter of disability is handled in my thesis. If I dare to leave my academic concerns aside for a moment, when I was a volunteer in a place wheresports and art programmes are organized for disabled people, I met with my friend Kübra who had cerebral palsy (CP). CP is a physical disability and it does not cause intellectual disability. However, I realized that when people meet someone who has CP, they react by raising their voices in order to approve what they hear or see although they do not understand the conversation or by basically ignoring them. I understand that if the "normal" is built regularly in everyday life, or prejudices occupy a larger space; what the situation is there, how communication is established, or subjective experience itself may not be so important. This experience allowed me to notice that what is to be "rehabilitated" is not the disabled perso but the perceptions about normalcy.

At the first place, the intersection of the family and disability appeared in my mind with the following question, “If the family is an active transmitter of social values, how much does the disabled child experience the "normal" of society through his/her family?” I did know that the first years of child is extremely important and the parents who have disabled child say that they had gone through some periods (sadness, guilt, acceptance, mourning, etc.). How was the disabled child was affected from these processes? This was the first question in my mind and it is still there. Then, I started to search about disability and family and the experiences of families with disabled children in the literature. The research on families was restricted. While I was working on the relations between family and disabled child, I noticed that all research I reviewed were dealing with the concept of *impact* of disability on families which implies the “bad influence” the disabled child had left on the family. (Dobson, Middleton and Beardsworth, 2001; Reichman, Corman and Noonan, 2008; Barak-Levy, Goldstein ve Weinstock, 2010; Girli ve Mutlu, 2015)

The theoretical framework of the thesis was shaped by these questions and tides. In first chapter, I trace the history of “normal” as a word and the meanings that it implies. *Ableism* (sağlamcılık) as one of the most essential notions of this paper and especially in the first part of this chapter, is constructed by demonstrating how normalcy is socially established. In the second part of this chapter, I examined the disability studies approach.

In the third part of the thesis, the history of disability, rights-claims, social movements and the disability policies in Turkey are discussed. In this part, I examine how citizenship and rights-claims were proceeding through the influence of globalization and neo-liberalism. Later, I discuss how disability policies and processes are structured in Turkey. Finally, it is discussed how the families with disabled children position themselves with respect to these policies and their effects on the family.

The fourth part of this chapter is organized in such a way as to deepen the discussion on how "normal" is established through the family. The family finds a place for itself in many different disciplines within the social sciences and also includes various contact points with the society. It is not possible to conduct a comprehensive family analysis and such an effort would have been illusive. Rather than this attempt, I emphasized that the interventions about the family is invisible through the core family and the concepts (marriage, blood relation, heterosexual love etc.) associated with it are normalized and ensured. Intervention is one of the key notions of this study because it is a avowed way of investigating the methods of the power for the reproduction of the normal and the restructuring of the disorder. While I was searching the literature of family studies in cultural psychology, I have come up with the notion of *cultural appropriateness* that is based on values and normalcy. In this part of the thesis, the cultural values assigned to the family and normalization of the one type experience and child - family relationship obstruct to exist with distinctive experiences. Such a view restricts the possibilities of the family with the disabled child. Finally, as I noted before, Çiğdem Kağıtçıbaşı's Value of Child research underlines how values appear in the family with their functionality. VOC research and its findings are exhibited on the axis of the questions stated above.

After identifying the thereotical basis of the thesis, scope of the thesis is extended to a field research and the narratives of the parents who have disabled children are explained. I suggest that this chapter has the most critical potential with regard to the meanings of the questions I have asked before.

The field research was usually conducted with the parents who already have connections with associations and foundations that are engaged in disability studies in Turkey. The interviewees were comprised of seven mothers and one father who have a child and children with intellectual or physical disabilities. The interviewees were not separated on the basis of the type of disability of their children being intellectually or physically disabled. The main purpose of this decision was the opportunity of staying outside of Mind/ Body dualism. It was predicted that such a distinction may classify the experiences at the beginning.

In-depth interviews were conducted in semi-structured form. It was observed that this method enables to share experiences instead of taking information in one-way (from interviewer to researcher). During the interviews, mainly the interviewers were asked what were their first feelings/ emotions/ ideas and how the process of raising their child changes their feelings. Another important subject of investigation was how they experienced the normalcy and the ableist society through their childrens' disabilities.

The theoretical frame installed below is also crucial for this thesis, but the main focal point of the study is the conducted field research. I would therefore like to reiterate that this thesis is meaningful because of the presence of the interviewees. The narratives of interviewers provide an opportunity for rethinking the notions and relations of society that are regarded certain, singular and perpetual.

CHAPTER 2

LITERATURE REVIEW

2.1. “ABLE” THE ROWDY

2.1.1. Relationality of Constructing Normalcy and Investigating Ableism

> “From where the government is injuring you, it becomes your identity.”
>
> Milan Kundera

If we want to understand the perception of society about the suıbject of disability, first of all, we have to analyze how society constructs and adopts the concept of ‘normalcy’. This thesis aims to assess that how individuals treat disabled people and disability in daily life and accordingly, how the entire society establishes the “norms” out of these daily perceptions.

People may have a tendency to think that the notions are eternal and perpetual. However, the meanings of concepts can vary over decades. Moreover, a word that is supposed to exist since the beginning of the language and culture could have been emerged at a closer time than we think in the history of language.

Throughout the thesis, I want to focus on the concept of "normal." The term is usually used by almost all the people at any time to indicate *average* situations.[2] In daily life, it is not stable like when it is located on a dictionary. Normal can be used as a noun or an adjective, however, when it is used to describe a condition with the intention of creating a consensus, it starts to pose a "danger." I present a deeper discuss about why it may be dangerous to use the term ‘normal’ in the next

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[2] The meanings of “normal” in TDK:

1. sıfat Kurala uygun, alışılagelen, olağan, düzgülü, aşırılığı olmayan, uygun
2. isim Aşırılığı, eksikliği ve taşkınlığı olmama, ortalama durum

parts of the thesis, however, in this section, I try to demonstrate how and when the word "normal" has been accepted to our language.

Lennard J. Davis, in his article *“Constructing Normalcy”: The Bell Curve, the Novel, and the Invention of the Disabled Body,* revolves around the questions about the concept of "normal." The first is, “was there any period in human history which the word ‘normal’ did not exist but a concept evoked ‘normalcy’? Finally, how would investigating the answers of these questions affect the disability studies? These questions draws the framework of this section.

In the beginning of the article, Davis suggests a striking thesis about the definition of "norm." The words like normal, normalcy, normality, abnormal implying "acceptable," "non-acceptable," average situations for public, have not been existed until 1840 both in the culture and in the English language. The most similar concept to “norm” existed in the Ancient Greek culture is called “ideal.” However, the word “ideal” cannot simply be compared with “normal”, because being “ideal” was a characteristic attributed to the Gods not to the ordinary people of Ancient Greece. Indeed, no one would expect a woman who lives in Crotona to be an “ideal” like *Afrodite*. Besides, any woman in Crotona cannot be "ideal” like Afrodite, because Afrodite was a combination of a mortal women and her perfectness consisted of one's face and another's breasts. So, we should investigate what happened in the history, which made “normalcy” the most desirable, convenient, essential state of being for humans?[3]

According to Davis, economic and class parameters were the most crucial factors in this transformation. Association of the middle class and bourgeois ideology initiated a change in perceptions of society in their most apparent values like beauty, kindness, or virtue. “The avarage man, the body of the man in the middle, becomes the exemplar of the middle way of life.” (Davis, 2006, p: 5) Day by day the middle class’s “new” values have been becoming visible for rest of the society. Statistics and other modern science methods also supported the

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[3] It should be mentioned here, The concept of "ideal" in Ancient Greece was not considered as a definite area of freedom and status.

convenience and obligation of “normalcy.” Novels extolled the values of normalcy, which were considered to provide the unique conditions of living a better life.

> The statement in Robinson Cruose in which Robinson’s father extols middle-class life as a kind of norm is a good example of this ideology:
> the middle Station had the fewest Disasters, and was not expos’d to so many Vicissitudes as the higher or lower Part of Mankind; nay, they were not subjected to so many Distempers and Uneasiness either of Body or Mind, as those were who, by vicious Living, Luxury and Extravagancies on one Hand, or by hard Labour, Want to Necessaries, and mean or insufficient Diet on the other Hand, bring Distempers upon themselves by the natural consequences of their Way of Living; That the middle Station of Life was calculated for all kinds of Vertues and all kinds of Enjoyments, that Peace and Plenty were the Hand-maids of a middle Fortune; that Temperance, Moderation, Quietness, Health, Society, all agreeable Diversions, and all desirable Pleasures, were the Blessing attending the middle Station of Life. (Defoe 1975, 6)[4]

Social science literature started to contribute to the rising of this perception. We usually tend not to associate the standardizing perspectives and revolutionary thinkers together. However, we can quickly give two examples about the relationship between these two. Eventhough they did not directly impose “normalcy” on society, *Marx* and *Freud* have been investigating "extreme" situations and people using different tools to "normalize" them. This was the effective way to create a homogenized and healthy society. Both of them composed thousands of ideas in their highly bulky works. So, they cannot be abruptly excluded from this thesis, instead, if their methods are analyzed carefully, the concept of "norm" will appear.

I have mentioned the “danger” of normalcy in the begining of this chapter and now, I want to offer some suggestions about how normalcy can become a harmful concept. Being healthy and stable cannot be problematised easily in daily life. From the very first years of our lives, the society teaches us how we can become solid, able-bodied, acceptable individuals. If your socialisation process continues in a "healthy" way and you avoid excessiveness, you become a regular member of society. Although this process is prescribed as a highly recommended method for

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[4] Ibid, p: 5.

“salvation”, it is not a key for a better life; nobody can assert that your life will be of full joy and happiness through this way. However, we can predict that being "normal" makes you invisible. Once invisibility is prescribed for a proper way of living, it will get easier to criminalize everything that seems out of norms. However, in my opinion, this perspective fails to notice that all human beings can be distinguished based on their different performances or existences. Thefundamental conditions of living together are not only limitedto to realize these differences but also requires to stand against discrimination, standartizing, ableism and disablism.

> My first claim is that the notion of ableism is not just useful for thinking about disability but also other forms of difference that result in marginality or disadvantage. Theory far from being abstract can help each of us make sense of our lived experiences and provide the tools for considering what is ‘going on’, to help us ask the critical and vital questions of contemporary life… The nuances of ableism are not static; they are transcategorical, having specific cultural alignments with other factors such as race, gender, sexuality and coloniality. Compulsory abledness and its conviction to and seduction of sameness as the basis to equality claims results in a resistance to consider peripheral lives as distinct ways of being human lest they produce marginalisation. Pointing to difference can be quite dangerous on a number of grounds. Differences can be reduced to the lowest common denominator, with attributable and immutable (pigeonholing) characteristics that can become signs of deviancy or delight. A call to sameness appears to be easier as these requests galvanise and *rearticulate the normative* even if such a norm is somewhat vacuous and elusive. (Campell, 2012, p:214)

Ableism (*sağlamcılık*) is defined as "a set of practices and beliefs that assign inferior value (worth) to people who have developmental, emotional, physical or psychiatric disabilities."[5] I underline this notion because it is mostly skipped in the studies of disability. Indeed, ableism can be overleapt because of the meaning it refers. Disability studies mostly focus on the disabled person rather than analyzing "normalcy" and majority's assumptions. This construction is based on a basic perspective about who assumes as the fundamental "issue” and who has to be rehabilitated in order to spirit the disability away. In the next

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[5] http://www.stopableism.org/

chapters of the thesis, ableism, and disablism will be deeply discussed because these notions can reveal the significant connections between disability studies and normalcy. In addition, assumptions and preconceptions of society about disability and the outputs of these assumptions are critical to this thesis.

It is useful to remark the risk of deeply conceptualizing the etymological roots of normalcy and how this risk arises. Focusing on normalcy may transform the disability studies. As it will be further discussed below, there are also some risks for engaging in a critique around norms in the way of making invalid the perspective that confines impairment body to medicine. In a rough statement, disregarding the "impairment" prevents to represent the disabled body with its performances and own abilities. Exactly as the opposite of what Social Theory[6] claims, it leaves the body into the medicine literature.

This thesis focuses specifically on the experience created by the reciprocal relationship between the family of disabled child and society. Thus, to interpret how the construction of the normalcy affects the ableist culture in Turkey will be the main focus of this thesis. Still, we should keep the experience of the impairment body -with its pains, specificity, and impairment- in our minds. This point will be discussed in the next parts of the thesis. Hereby, I will interrupt the process of tracing the etymology of "normal" and start to discuss which connections make the ableism apparent in Turkey.

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[6] The continuation of the argument can be seen at pages 13,14 and 15.

2.1.2. An Impossible Struggle: Demonstrating the Representations of “Ableism” in Turkey

I have to admit that this chapter is one of the toughest parts of the thesis. It is overtly challenging to draw a picture of a substructure for ableist view through demonstrating politics of government and tools of culture. In addition, the notions like modernity, individuality, nation-state should be investigated and defined if we attempt to conduct such research.[7] Rather than to maintain ungrounded and separated debates, I suggest utilizing Hannah Arendt's conceptualization of "evil." To continue this argument by this method may enable not to radicalize one specific period in the history of Turkey and not to limit the investigation to politics and ethical values which emerge in a significant period in Turkey. This view definitely is not a disdain of establishing a historical basis, on the contrary, this struggle tries to point out that the perspectives related to modern thought that can emerge in all aspects and at all times of modern life. In other words, even if some crucial conditions, such as economic systems, change, the legitimacy of the colonial nation-state mentality, which compose the entire European political thought, the dualism and modern bureaucracy and separate the humans as "me" and "others", the Enlightenment putting human minds instead of God's idea, cause appearing the "evil" in anywhere and anytime.[8] Thus, I mainly attempt to explain how marginalization directly or indirectly affects disabled people and the daily practices of ableism with examples.

We tend to forget that our definitions, values, even experiences emerge as a result of a historical process, and also the nation-states set themselves up as eternal and perpetual. This is actually ironic because the political powers can redraw some parts of the history as they want in the direction of their own interests. We are guided by a historical perspective in which the rulers want to legitimize themselves.

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[7] The notions have been mentioned here will be used in order to establishing the critcal relations between modern family of Turkey and approaches to disability in Turkey. But researching the etymological roots of these concepts separately is not the desired method to use in this thesis.

[8] “The evil” be used here in a metaphorical sense.

I do not claim that the power is endlessly inclusive and restrictive, but I argue that especially the modern states can function as an oppressive surveillance and control entities. This anxiety of control is manifested in the female body, which is often tried to be held with the positioning of woman in public and private space.

In the *Image and Imperialism in the Ottoman Revolutionary Press, 1908-1911,* which Palmira Brummett examines Istanbul satirical press and artfully weaves the narrative and images of political, economic, and cultural transformation to create a new vision of the Middle East at the end of the empire, after the Ottoman Constitutional Revolution of 1908, she analyzes a detailed image of a woman. It is absorbing how the satirical magazines established the state/woman relationship. Fashion was used to identify the women who raised the honor of the empire and the women who trampled on the country. Fashion represented that Europe deludes the empire and how the Ottoman Empire resists it. The humor press in some cartoons showed the Ottoman State as a prostitute of Europe. This prostitute wore an exaggerated hat, a dress from Paris. The threats like the sex, the clothes, the extravagance and the imperialism were illustrated through the woman dressed according to the fashion (Brumett, 2000).

I assert that the establishment of the Republic of Turkey and especially the one-party period cannot be considered separately from the Tanzimat period of the Ottoman Empire. Rather than a natural essence as claimed,[9] history and culture can not be interrupted.

> Nevertheless, the real break occurred with the founding of Kemalism and the Republic. The secularization of the family law and the recognition of the right of women to elect and to be elected were the veins of a more comprehensive struggle, as the Tekeli detected very accurately, to overthrow the theocratic walls of the Ottoman state and to create an ideology to legitimize the new state. Meanwhile, the "new woman" of the Republic of Turkey was on the front line in symbolizing the regime: She performed with shorts in ceremonies, carried the flag with school or military uniform or danced with western fashionable evening dresses in balls. (Kandiyoti, 2011, pp: 191,192)[10]

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[9] For the essential arguments of Ziya Gökalp which act a huge part at establishing the Republic of Turkey can be look at his texts like "Gökalp, Z, *Kitaplar,* 2007"

[10] Translated to English from original: Yine de asıl kopuş, Kemalizm ve cumhuriyetin kuruluşuyla gerçekleşti. Aile yasasının laikleştirilmesi ve kadınlara seçme seçilme hakkının tanınması,

At first glance, it may be seem unsuitable to mention about the women's representations in the last period of the Ottoman Empire and at the early Republican period. The first reason is that I have considered it as a proper way to point out cultural continuity resulting from the modernity idea in the geography we live. The second reason why I have tried to look at how the woman was constructed is that the family carries an active role in the "tasks" of woman and in the representation of woman, which will be discussed in detail in the following sections of the thesis. Thirdly, I wanted to show that the biopolitics is not only about disability, but also about all the groups that are "suspicious" in the public spaces.

Similar to women, children also play a part in the establishment fantasy of the nation state. In my opinion, it is closely related to the view how the child is presented/idealised and to the investigation of disability/ableism which will be structured through the analysis of modern family in the next chapter of the thesis. The article of Itır Erhart and Hande Eslen-Ziya (2013) in which they investigate the values, attitudes, beliefs and ways of thinking, and the common characters used in children's books, and the central role and activities identified with these characters will be elucitador for this argument.

> A similar pattern was observed in the construction of Turkish children and childhood. Indeed, children, almost entirely, are defined in the world of their mother through the discourse of childrearing. As Öztamur said:
> '…With the advent of the word 'modernization', child-raising has become a part of the world of almost exclusively mothers, and the aim is to create a new child who is physically, mentally and morally healthy, robust and fit and who is raised in accordance with modern, rational and hygienic principles; it has become the creation and production of new children types.'(Öztamur, 2004: 17)
> All of the policies adopted at this time (the early 1930s) have focused on the training of generations, both physically and morally healthy. The discourse used in the framework of the ideal child-raising project is very close to the rhetoric used to create Turkish women: creating an 'ideal' nation-state.[11]

Tekeli'nin çok doğru olarak saptadığı gibi, Osmanlı devletinin teokratik surlarını yıkmak ve yeni devleti meşrulaştıracak bir ideolojiyi oluşturmak gibi daha kapsamlı bir mücadelenin öğeleriydi. Bu arada Türkiye Cumhuriyeti'nin "yeni kadını" rejimin simgeleştirilmesinde ön planda bir rol aldı: Törenlerde şortla gösteri yaptı, okul ya da asker üniformasıyla bayrak taşıdı ya da balolarda Batı modasına uygun gece elbisesiyle dans etti.

[11] Translated to English from original: Türk çocuklarının ve çocukluklarının inşasında da benzer

This section is not based on examining the conditions of discrimination in Turkey in particular. One reason for this is the process of biopolitics that works through production of new images and reproduction of these images, which is analyzed below. The other reason is that it requires to demonstrate the historical and sociological prossses that caused the discrimination and counter policies like identity politics of minorities elaborately.[12] However, in this thesis, it is not the discrimination itself to be investigated, but the perceptions of normality in society and the ableist view leading to discrimination.

This thesis also includes an idea of how the disability is experienced in Turkey. It is thought that the most effective way of examining the ableism is to look at the direct experiences of people. That is why I have preferred to include the experiences of people in this study. In the next section, disability theories will be discussed through the mind/body duality, and thus, it may be easier to grasp the standpoint of the families with disabled children.

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bir kalıp izlenmiştir. Nitekim, çocuklar, neredeyse tümüyle, çocuk yetiştirme söylemleri üzerinden annelerin dünyası içinde tanımlanmışlardır. Öztamur'un söylediği gibi: " ... 'modernleşme' söyleminin gelişiyle birlikte, çocuk yetiştirme, hemen hemen mün- hasıran annelerin dünyasının bir parçası haline gelmiş, amacı da, ziksel, zihinsel ve ahlaksal olarak sağlıklı, gürbüz ve zinde olan ve istenen modern, rasyonel ve hijyenik ilkelere uygun olarak yetiştirilmiş yeni çocuk tiplerinin yaratılması ve üretilmesi haline gelmiştir". (Öztamur, 2004: 17) Bu dönemde (1930'ların başları) benimsenen politikaların hepsi, ziksel ve ahlaksal olarak sağlıklı olan nesiller yetiştirilmesi üzerine odaklanmıştır. İdeal çocuklar yetiştirme pro- jesi çerçevesinde kullanılan söylem, Türk kadınları yaratma çerçevesinde kullanılan söyleme çok yakındır: 'ideal' bir ulus-devlet yaratmak.

[12] For more information about Discrimination in Turkey: Ayrımcılık Çok Boyutlu Yaklaşımlar (Çayır and Ayan- Ceyhan, 2012)

2.2. TRACING DISABILITY STUDIES

Decartes has set the foundations of mind/body duality that the modernity attaches to the heart, by defining the body as a notion which prevents the search of the truth for the sake of good life. Therefore, the truth is the whole of the propositions that can be investigated only with the systematic and definite arguments of the mind. Decartes starts to think suspiciously of all the information around him, and ultimately, the only truth he cannot doubt is that his mind is in a position of thinking. In a kind of way which is obviously not innocent, the argument "I think, therefore I am" gives the power to change everything in their vicinity which the modern humans accept as naturally present in themselves. In this way of thinking, the body is placed in a position of doubt about its existence. The ability to know herself and outsiders (who are now completely disconnected from each other and the nature) is gathered in the spirit, which Descartes has called the *substance*. The body often appears as a reflection of human nature[13] with malignant desires and the mind is obliged to control the desires of the body by using the power of will. These ideas constitute the essence of modern science by attributing precise values to the modern self, and the modern society which the individuals have created/transformed, and the object they are seeking in return for accurate information.

In this section of the study, I discuss how the definitions of disability and theories of disability are influenced by the thoughts stated above. First of all, the medical model which declares that “Disability is an impairment itself” is examined. Then, the connections between Social Model of Disability that are still endorsed by the majority, and the already accepted norms of society are discussed. In other words, how the social model ignores idiocritical performances of impaired body and through this how it turns back to the Cartesian Dualism are problematized.

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[13] “Nature of human” has been becoming the one of most popular subjects of debates for both essential and non- essential theories of social sciences. In this text it is used by the meaning which Decartes refers in his *Meditations.* In the second meditation has started this argument: “The nature of the human mind, and how it is better known than the body.” (Decartes, 1984, p:16)

The subject of disability appears in the field of medical science when the medical science attempts to replace its “object” of the self-assured attitude of modern medicine with its certain knowledge of the "normal" body. The idea that disability is an impairment itself exactly fits to the perspective of modern medicine.

> Biomedicine has as its focus individual deviations of body and mind from socially recognized norms. İmpairment *per se* is of central concern – its detection, avoidance, elimination, treatment and classification –though chronic and degenerative diseases remain hard nuts to crack. Much biomedical hope and expatation are currently invested in a fast-moving genetic science which appears to its practitioners to offer a brave new world of diseases eradicition and radical new tratements for the restoration of normal functioning. In this medical model perspective, disability continues to be equated with the impeairment itself –‘the disability’ is the impairment. (Thomas, 2002, p: 40)

Defining the body without a historical background leads to the idea that all bodies are "the machines" that have to process properly. If doctors can "fix" the impairment, why they do not succeed in doing it? It is known that the modern medicine works with statistics and when statistics approaches disabled people as the people who can be fixed or cannot be fixed, it renders discrimination alive.

As I mention below, thanks to the Social Model of Disability, disabled person particularly has been free from the methods of modern medicine, but it is hard to make the same statement for impairment body. Because of the scholars who teorise the social model, tried to pull every notion and concept of disability to the social side, the medical model and social model remain within a dualist conflict.

The biological	**The social**
impairment	disability
the body	society
medicine	politics
therapy	emancipation
pain	oppression
the medical model	the social model

The most known opposition to the idea that “Disability is an impairment” is the "Social Model of Disability." The theory usually says that the "disablist" for disabled people does not the impairment itself but the norms of society. Such a view has retracted the subject of disability from the individual and pathological aspects to the cultural arena, and has strengthened the emphasis on the concepts of civil rights, and social justice. As an achievement, it paved the way for the practice of resettling the individual experience in the social area. However, this theory misses the attempt to think about the body itself. Imagining an exact difference between socially produced disability and impairment body does not save the body from the ambivalent world of the Cartesian dualism. On the contrary, this way of thinking disregards the performance of the body and forces it into the medical literature by dissolving it in what is normal.

> In the social model, the body is rendered synonymous with its impairment or physical dysfunction. That is to say, it is defined -at least implicitly- in purely biological terms. It has no history. It is an essence, a timeless, ontological foundation. Impairment is therefore opposite in character to disability: it is not socially produced. With respect to the body and impairment, the social model makes no concession to constructionism or epistemological relativism: it posits a body devoid of history…. Indeed, there is a powerful convergence between biomedicine and the social model of disability with respect to the body. Both treat it as a pre-social, inert, physical object, as discrete, palpable and separate from the self. The definitional separation of impairment and disability which is now a semantic convention for the social model follows the traditional, cartesian, western meta-narrative of human constitution. The definition of impairment proposed by the social model of disability recapitulates the biomedical `faulty machine’ model of the body. (Hughes and Peterson, 1997, pp:328,329)

The social model has to do with determining which aspects of disabled people’s lives need medical or therapy interventions, which aspects require progressive politics, and which aspects require political action. For this reason, it creates a series of opposition between social/biological, politics/medicine, body/society, pain/oppression, therapy/emancipation, disability/impairment (Ibid, p: 69). The statements of Judith Butler about the politics of construction of bodies and her ideas that enable queer theory are discussed elaborately in the next part of this chapter. However, I want to quote from Butler's *Gender Trouble* in order to draw attention to what the social model entails through ignoring the impairment body. In this quotation, “gender” can be altered with “disability.” “When the relevant “culture” that “constructs” gender is understood in terms of such a law or set of laws, then it seems that gender is determined and fixed as it was under biology-is-destiny formulation. In such a case, not biology, but culture, becomes destiny.” (Butler, 1990, p:8)

One thing we have to be very cautious about is the essential idea that a study fighting for the equal opportunities and a practice that is trying to include disabled people in the society can easily open the door to make biopolitics visible, which is further elaborated in the next chapter. It is a suitable example for this concern what Fatma Sahin, the former Minister of Family and Social Policies, has said:

> In 2011, General Directorate for Disabled and Elderly Services was established under the roof of the Ministry of Family and Social Policy to increase the quality of life of our disabled citizens with a "rights" based approach and to provide service oriented. As the Ministry, all citizens with disabilities with an understanding of "a life that exceeds the limits of the disabilities"; we provide services to take all necessary measures to ensure effective participation in social life, benefit from equal opportunities, exercise their rights and be productive.[14] (p: 5)

It is useful to specify right here the purpose of telling them to never underestimate what is done throughout the project. It only shows how easy it is for a theory that does not tear the dominant idea down to serve the politics of normalizing the disabled people and trying to make them "more productive”.

Foucault hit the backbone of the Cartesian Dualism when he revealed that the process of "subjectivism" by the method of walking through the concepts of madness, sexuality, crime objectified the same subject very clearly. Foucault's texts, at the same time, opens the way for the subject to "get rid of" the networks of power established at every level, everywhere and to produce different subjectivities. The

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[14] Translated into English from original: “Hak” temelli anlayışla, engelli vatandaşlarımızın yaşam kalitesini artırmak, talep odaklı değil arz odaklı hizmet sunabilmek amacıyla 2011 yılında Aile ve Sosyal Politikalar Bakanlığı çatısı altında, Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü oluşturulmuştur. Bakanlık olarak; “engelleri aşan bir yaşam” anlayışıyla tüm engelli vatandaşlarımızın; toplumsal yaşama etkin katılımını, fırsat eşitliğinden yararlanmalarını, haklarını kullanabilmelerini ve üretken olabilmelerini sağlamak amacıyla gerekli tüm tedbirleri almak için hizmet üretiyoruz. (*Engelsiz Bir Türkiye İçin: Yolun Neresindeyiz?* (Mart, 2013)

subject, despite its establishment, can create a power to change this setup with per say processes of subjectification. The "process of becoming a subject" can invent new life possibilities. It can create new ways of being (Demirtaş, 2014). In Foucault's essays, the subject is not revoked and defined by an eternal free, rational, individualistic, transcendental existence which is utterly eluded of its power nets, and the subject is not limited to its already produced meanings of the language.

It is reasonable to look at the ways in which the bodies enter the field of power after pointing out how the process of subjectivity works. In its roughest expression, biopolitics is the struggle to put the bodies into the cycle of capitalism by making them more *productive*. The power mentioned here is Foucault's definition of the power, which is not accumulated in a centralized hand, but it is distributed to the whole. Moreover, in Foucault's conceptualization of power, the power does not operate by using prohibitions or obligations. It is a great producer, it produces and reproduces meanings all the time and every where, and mostly those strategies through the use of meanings and knowledge construct the power of which the tools are invisible.

> Why is this juridical notion of power, involving as it does the neglect of everything that makes for its productive effectiveness, its strategic resourcefulness, its positivity, so readily accepted? In a society such as ours, where the devices of power are so numerous, its rituals so visible, and its instruments ultimately so reliable, in this society that has been more imaginative, probably, than any other in creating devious and supple mechanisms of power, what explains this tendency not to recognize the latter except in the negative and emaciated form of prohibition? Why are the deploy- ments of power reduced simply to the procedure of the law of interdiction? (Foucault, 1978, p:84)

As mentioned in the introduction of this section, this form of thought constituded by Foucault influenced all the conceptualizations against the essentialism, including queer theory. How the power and norms construct not only gender but also the bodies of society was the main question for Judith Butler. She has problematized the feminist theory which investigates "gender" as a notion that is established by culture, norms and society. As I have mentioned earlier, conceiving the gender as a complete set of rules that inflicts the passive body includes the danger of "making it a kind of fate".

By praising the outside of norms and being left out of norms, queer theory violates the normative domain, which provides opportunities for renaming and reproducing "strange, odd, weird, even bad, sick and abnormal."[15] (Güçlü and Yardımcı, 2013, p:17) "The term "queer" has operated as one lingusitic practice whose purpose has been the shaming the subject it names or, rather, the producing of a subject through that shaming interpellation." In fact, queer enables its power being shaming and pathologized. (Butler, 1993, p: 226) There are many comprehensive debates under the roof of the queer theory. In this study, I examine the aspect of queer theory that opens a way to other forms of *existence* through conceptualizing the impairment body in the disability studies, and problematizing being "disabled person" and disability as an identity. The thesis of queer makes it possible to contemplate the identity discources. Demanding political rights from power by creating identity categories involves difficulties. Firstly, it is not possible to completely speak outside of social norms and power. Besides, it may be easy to be seized by language of power. Second, it is hard to position in a perpetual condition which is trying to define identity in isolated terms from history. This struggle is interrupted "by the history of usages that one never controlled, but that constrain the very usage that now emblematizes autonomy; by the future efforts to deploy the term against the grain of the current ones, and that will exceed the control of those who seek to set the course of the terms in the present." (Butler, 1993, p: 228) Even though Butler does not completely deny the politics of identity, she warns about its risks that will emerge when the possible conflics are ignored. If identity processes as "a side of collective contestation" it can remain as *queered*. This view has a possibility to generate the disabled body with its all "undesired existence".

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[15] Sibel Yardımcı and Özlem Güçlü have compiled the texts can be defined as a "key" for queer literature in their book, *Queer Tahayyül*. They have mentioned that "queer" means "garip, tuhaf, yamuk" in Turkish language.

It can be asserted that queer theory is also very important for a debate about the body. However, it seems useful to return to Foucault for a moment before discussing how it would be possible for the body to deal with its suffering, otherness and nonfunctionality. Foucault's conceptualization of the *biopower/biopolitics* gives us an initial idea about how the body is established and what can be the opportunities of this construction.

The most important condition that enables biopower is the relationship that it establishes closely with knowledge of the body. As Foucault defines on the chapter “Right of Death and the Power of Life” in *The History of Sexuality*, “bio-power created in the eigh- teenth century as techniques of power present at every level of the social body and utilized by very diverse institutions (the family and the army, schools and the police, individual medicine and the administration of collective bodies), operated in the sphere of economic processes, their development, and the forces working to sustain them.” (Foucault, 1978, p: 141). Bio-power regards the society as an economical value for power. “The mechanisms of power are addressed to the body, to life, to what causes it to proliferate, to what reinforces the species, its stamina, its ability to dominate, or its capacity for being used.” (Foucault, 1978, p:147)

The subject of body has appeared in social sciences as a form of production through its historical background and productive existences, which makes a big difference in terms of the perspective towards disabled bodies as it is for all the bodies that cannot be adopted easily in the cycle of capitalism. Biopower, as defined by Foucault, is transfered to the society not only through politics but also singular, effective, useful, sustainable bodies. It is almost completely dissimilar to make it visible with its impairment and "nonfunctionality" and trying to include it into normal, productive way. The problem that the social model of disability recreates by ignoring discursive construction of the body is that it obliges the disabled body to penetrate into the field of medicine to be treated/cured and leaves it in therelations of bio-power as previously stated.

When Judith Butler introduced the notion *disidentification,* she did not deny all identification politics. She basically pulled the body into discoursive area like identifications still exist. Actions, desire and movements of body can be considered with *performativity.* Butler’s performativity cannot be conceptualized entirely outside of the discourse of power, in fact, it produces a opportunity by *repeating* the practices of norm and power. The fact that the gendered body is performative means that there is no ontological status separate from the various acts that constitutes its reality. “If the “cause” of desire, gesture, and act can be localized within the “self” of the actor, then, the political regulations and disciplinary practices which produce that ostensibly coherent gender are effectively displaced from view.” (Butler, pp:173, 174)[16]

Desire and pain are two critical notions which make the impaired body invisible. Disabled people are mostly considered as *desire-free*. Although the word “desire” does not give the intended meaning in this sense, the sexuality of disabled people tends to be ignored. In other words, ignoring one’s desires is an easier way to reach *naturalization*. Elif Emir Öksüz who is visually a disabled person, in her article about one of the titles of *Ekşi Sözlük*[17], “The Advantages of Having Sex with a Blind Girl”, writes this sentences: “I have been not mad to this title. Maybe it sounds a little weird, but it's also kind of fun. Do you know what I felt? Some people are aware that blind people are also having sex.”[18]

Marriages that occur between two disabled people, as well as between other people with "abnormal" bodies, are followed by a foreign acceptance. The theory of social construction postulates the body with its pleasure, the body is “naturally”

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[16] It is deeply known, for a comprehensive debate, I have to mention about how Deleuze and Guattari characterise the “desire” and theorize “the body without organs”. Including Butler, many of anti-essential social scholars utilize those conceptualizations when they compose their theories about the “body.” However, it is not possible to maintain the argument with this massiveness. In *Anti- Edipus Capitalism and Schizophrenia ,* Deleuze and Guattari overthrow the fixed relation between the subject and the object, they place the desire on the basis of a perception in which everything is regarded as a machine that produces the truth (Deleuze and Guattari, 1983).

[17] One of the biggest online “communication points” in Turkey

[18] http://bianet.org/biamag/toplumsal-cinsiyet/161913-kor-bir-kizla-sevismenin-avantajlari

trainable and adaptable. “The human ego does not easily accept the disabled body. It desires pleasure. Perhaps, this is because, as Freud explained, the ego exists on the surface phenomena and superficial glimmers of enjoyment.” (Siebers, 2008, p: 60)

Although the outputs of the desire like pleasure are incorporated into the “normal” area, the pain is easily attributed to the other. “Pain has often been described as a private, even lonely experience, as a feeling that I have that others cannot have, or as a feeling that others have that I myself cannot feel.” (Kotarba, 1983: 15).[19] According to Sarah Ahmed, “the labour of pain and the language of pain work in specific and determined ways to affect differences between bodies.” (Ahmed, 2004, p: 23) Although it looks unfair; pain is crucial to the formation of the body as a perceiving surface. “Insofar as the body tends to disappear when functioning unproblematically, it often seizes our attention most strongly at times of dys- function.” (Ibid, p:26) Pain, like the body itself, is not disconnected from its ties to the other, is not essential and specific, but rather closely related to experiences. “The sociality of pain – the ‘contingent attachment’ of being with others – requires *an ethics*, an ethics that begins with your pain, and moves towards you, getting close enough to touch you, perhaps even close enough to feel the sweat that may be the trace of your pain on the surface of your body” (Ibid, p:31).[20]

Finally, the opportunity for another method is investigated; the impairment of the disabled body is not excluded, ignored, or lost in “normal” state. The disabled body, even if we do not want to see it or we ignore it, is "real". If there is pain, it does not have to be evacuated. If we want to talk about possibilties, we have to start to think about interactions, surfaces and experiences.

The reason I have traced the disability theories basically is to understand the "disability" through an investigation of the family/disabled children relationships. Disability is not independent of the relations of power both in the context of social norms and in terms of the ways by which the disabled bodies are established. In my

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[19] Quoted from Ahmed, S., *The Cultural Politics of Emotion,* 2004.

[20] Emphasis is mine

opinion, it must be observed of by this method. Obviously, the interface in this thesis is the modern family since the family is a reproducer of social norms “as a basic unit of society” and it experiences the disability through the disabled child.

One of the aims of this study is to understand how the disability experiences of the families with disabled children are built in response to disability policies. Investigating the disability experiences of families is a struggle for both to increase the opportunities for families in their daily lives and to contribute the family related areas of disability policies through these experiences.

2.3 SOCIAL POLICIES FOR DISABLED PEOPLE AND HOW THESE POLICIES AFFECT FAMILIES WITH DISABLED CHILDREN IN TURKEY

Defining the disability as a medical issue affected disability policies directly. Modern medicine equated “impairment” with “disability”, which reveals a discriminative perception about disabled people. This perception approved that disabled people have to be “fixed” and adapted to society. It can be said that the medical approach to disability has made a distinction in the daily lives of healthy majority and disabled minority. This difference created certain social policy views about disabled people. An approach has developed through the idea of help, which defines disabled people as a disadvantaged group. Medicine was the decision mechanism that could determine who was disabled, and only those "identified" people could benefit from the government's support (Yılmaz and Yentürk, 2017). The social policies that are based on a medical approach to disability has lost their strength, especially in Western Europe, after the disability rights movement became more visible (Ibid, p: 61).

The social model represented a great improvement with respect to social policies. The problems which disabled people faces were not because of their own "differences". The problems were based upon the relations that the society produced with an ableist view. Therefore, this model argued that social policies should aim to transform the social relations (in a cultural, economic and political way), not disabled people themselves (Ibid, p: 61). It is not possible to say that the medical approach does not affect disability policies, but it is clear that the social model is also influential in claiming for rights.

Bezmez and Yardımcı, in their articles based on the disability rights through the transformation of the perception of citizenship in Turkey, trace the unity of the state and civil society in the process of rights- claims in Turkey (Bezmez and Yardımcı, 2010). "The economic liberalization and cultural globalization of the 1980s, as well as Turkey's more recent accession process to the EU increased the visibility of non-Turkish and non-Muslim identities, and made possible the development of a new language of rights." (Ibid, p: 606) Kadıoğlu defined this process as "denationalization of citizenship" (Kadıoğlu, 2007, p:283; Ibid, p: 606). Citizenship was reconstructed as an area where active participation is possible in the processes of defining the rights, rather than being considered as a state-provided status. However, it should be mentioned here that Turkey has experienced some specific situations during the process of "transformation of citizenship". The perception about citizenship in Turkey was formed around "duties", "strong state tradition" and "the prioritization of the public good before individual interests". (Ibid, p: 606) Bezmez and Yardımcı also suggested that the military coup of 1980's also had a negative effect on the social movements and struggles of people with disabilities.

Another difficulty encountered in the practical aspects of rights-claims of people with disabilities is defined as a charity-based, protectionist approach. Ayşe Buğra (2008) reveals the foundations of this approach with her distinctive view about the continuity between Ottoman Empire and Republic of Turkey. The Republic of Turkey inherited a centralized governmental system from the Ottoman Empire which influenced even the present social policies. The Ottoman Empire dealt with many social issues in the fields of health, education and poverty, however, the state tried to solve these issues through "charitable foundations". Interestingly, this approach paralleled the social policies of the Republic of Turkey.

In the period when CHP (the Republican People's Party) was the single party, social policies were left to non-governmental organizations. Justice and Development Party (AKP) "which longed for reviving Ottoman roots in many aspects of cultural life took the opportunity that economic decontrols of the post-1980s created to institutionalize a system of charities integrated with the state." (Buğra, 2008; Bezmez and Yardımcı, 2010, p. 607). While AKP has begun to reach more people through its "charity- oriented" approach, the people who rejected to adopt this social policy approach have been increasingly marginalized (Buğra, 2008; Bezmez and Yardımcı, 2010, p. 607).

The last issue to be emphasized before reviewing the history of disability policies in Turkey is the importance of Islam and the culture it creates around its values. According to Bezmez and Yıldırım, "Islam has almost always played a crucial role in determining the way people with disabilities perceive themselves." Their article includes interviews with the members of two NGOs (the Association of People with Disabilities of Turkey and Disabled and their Friends Platform). The impact of Islam has been investigated through in the interviews. According to Engin Avcı, "The perception that disability is as a form of being put to test in front of God and that one should be thankful under any circumstances, limits the prospects of a rights-based attitude, of feeling as having the right to have rights, and of being ready to fight for those" (Bezmez and Yardımcı, 2010, p: 608).

> Secondly, the perception that people with disabilities are in need of help and that the provision of such help is meritorious in religious terms has almost always shaped the encounters between people with and without disabilities. One interviewee reported that a mobility-impaired friend of his was frequently given money by passersby who believed that he was asking for money, or would at least be happy to receive it (interview with Bülent Küçükaslan). (Ibid, p: 608)

Disability is associated with the feelings of "compassion" and "understanding" rather than a "legitimate political struggle for citizenship rights" (Ibid, 608). This may cause disability to be considered as a situation that "must be compliant if the needs are met " and it may make a discriminatory attitude towards disability legitimate.

It can be said that NGOs have been critical to the rights-claims of disabled people. Therefore, they can be criticized for the relations they establish with the state. Nevertheless, it should be noticed that there are potentials depending on the forms of organization (Ibid, p: 613). We see that the first disability rights movements in Turkey began to be supported by two NGOs established in 1950 and 1960 (Yentürk and Yılmaz, 2017, p: 62). The issue of disability was adopted by the welfare state policies as a category of need in 1970s. “The introduction of compulsory employment quota” and “non-contributory disability allowance” can be considered as the first wiggles of social policies for disabled people (Yılmaz, 2010, p: 160). It can be said that the political interest in the problems of the disabled people has increased by the “Law on Disabled People” in 2005 (Yılmaz and Yentürk, 2017, p: 62).

Although the number of people reached during the AKP period through "charity- oriented" approach (Buğra, 2008; Bezmez and Yardımcı, 2010, 607) and the public expenditures have increased (Yılmaz and Yentürk, 2017), there are strong criticisms of these policies. One of these criticisms is that access to government services for disabled people depends on a health report. People whose disability rate is below 40 percent cannot benefit from these services. “... the total number of people officially registered as disabled in November 2009 was 675,137,257 which is quite low when compared to more than 1.7 million or 8.5 million (with chronically ill) found by the Disability Survey conducted in 2002” (Yılmaz, 2010) This practice separates the community as disabled and non-disabled and positions the disabled people in the disadvantaged target group (Yılmaz and Yentürk, 2017, p: 63).

Another criticism of how disability policies are structured is also important for this thesis, which investigates the disability experience of the families with disabled children. Cash-for-care policies have become more visible in AKP period of which one of the widest expense items is "at-home care allowance" for which “the eligibility for at-home care allowance is based on having an income below a specified threshold” (Yılmaz, 2010, p: 142). The clear distinction between institutional care policies and at-home care policies is not only the people who are targeted.

> By supporting the family to take care of its disabled member(s), this policy preference neither challenges the gendered division of labor in family, nor supports independent living for disabled people. Hence developments in the area of social policy brought by the Law on Disabled People implies both liberal residualism with regard to restricted coverage of the programs, and conservative outlook due to its ideological commitment to the myth of family solidarity. (Yılmaz, 2010, p: 172)

Similarly, in field research of this thesis, it was seen that the mother is most related to the child in the family and basic care of the disabled child is provided by the mother. It can be argued, this situation is forcing the disabled child to stay in the private spaces and deepening the roles based on gender.

2.3. LOOKING AT THE “NORMAL” CLOSER

2.3.1 What does Normal/ Nuclear Family mean in Turkey?

Trying to examine the family through sociological concepts requires a great deal and effort. The researcher should be able to look at its subject from different perspectives such as economical, political, cultural, geographical, even biological and keep the interactions between them in mind. Besides, the historical changes and the effects of these changes on the family’s moving structure becloud this struggle. It is not alleged here that the family construction in Turkey is subjected to explicit analysis throughout this section. Rather, the family is investigated through the discourse analysis and the representation that is mostly fictionalised by the power. As I indicate below, according to power, the family is a key to regulate sexuality and eliminate the problems created by the industrial community which are - often being covered up-. Thus, the modern family has become one of the dominant actors of politics produced for the “order” of society.

It may seem like a cliché to give a definition from TDK (Turkish Language Institution) [21] when trying to open a nation. However the sembolic system of the language can be one of the useful ways of tracing how the notion spread to various levels of society. In TDK, the first meaning of family appears as "the smallest unity in society, which is based on relationships between marriage and blood, the relations between the wife, husband, children and siblings".[22] If this definition is deeply examined, we see the popular ideas about the family clearly. Regarding the family as "the smallest unity of society" is to assume all the relations and conflicts of entire society encapsuled in the family as well as considering the family as a crucial component for producing the norms of society. This idea natually gives a political sphere to the structure of family. The second point in this definition "marriage and blood" implies that being a family always requires a marriage and the relation based of blood. Marriage needs to be recognized in front of law, which brings the obligation of recognition of regular sexual identities. According to Connell (1990), "the state is bearer of gender (though in a much more complex way than ideas of the male states suggests). Each empirical state has a definable "gender regime" that is the precipitate of social struggles and is linked to -though not a simple reflection of- the wider gender order of the society." (Connell, 1990, p: 523) Although especially in the last decades, marriage has been legalizing gender identities of LGBTI around different nations of the world, in Turkey, marriage is a right for only heterosexual citizens.

Marriage can be defined in different geographies and historical periods by several forms but whereever we turn our heads we find a crucial component about marriage: legality. Legality can face some objections in the area of Islamic marriage. Even though, in the Islamic marriage, legality takes place not in front of the laws but before the God. "It is only possible for a family to have a body in law by only a precise marriage. A genuine marriage that allows the husband and wife to legitimately unite can also be seen as one of the parties propose the marriage and

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[21] Türk Dil Kurumu (Institution of Turkish Language)

[22] Translated in English from original: "Evlilik ve kan bağına dayanan, karı, koca, çocuklar, kardeşler arasındaki ilişkilerin oluşturduğu toplum içindeki en küçük birlik."

the other accepting the proposal. It is not possible to perform a marriage with unfamiliar ruin or superstition. In other words, according to Islam, there is a kind of marriage that has its stipulations and well-being." (Aktan, 1992, p: 398)[23]

According to the functionalist approach, the family is one of the organs, even the most basic, that allows the community to continue its ordinary and decent operation, in other words, to maintain its "normal" dynamics. The family does this by fulfilling some basic tasks. According to Parsons, family has two main functions, "We therefore suggest that the basic and irreducible functions of the family are two: first, the primary socialization of children so that they can truly become members of the society into which they have been born; second, the stabilization of the adult personalities of the population of the society." (Parsons and Robert, 1956, p:16-17) Apart from these basic functions, the family can be described as an area where economic production, care of sick and elderly, recreation and reproduction take place.

As one of the main organs of society, the family not only affects the society directly, but it is also influenced by the changes and transformations of society. For instance, Parsons (1960) alleges that in the pre-industral era, extended family was a predominant model in the society, because the labor-intensive production was more common and the family was the basic production unit. However, in the industrial society, family is not a main unit of production itself, on the contrary, it starts to turn into a consumption unit. In addition, the members of the new/nuclear family have to have some abilities and skills about adaptation, translocation and migration.

Observing the family through the functionalist theory may seem out of date but still macroanalyses about the family use the functionalist methods to explain the family structures. Especially the researches initiated by the power are inspired

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[23] Translated into English from the original: Bir ailenin hukuken vücut bulması ancak sahih bir nikah ile mümkündür. Karı kocanın meşru olarak birleşmesine imkan veren sahih bir nikah da taraflardan birinin icabı (evlilik teklifinde bulunması), diğerinin de bu teklifi kabul etmesiyle vücut bulur. Sahih olmayan fasit veya batıl nikah ile ailenin oluşması mümkün değildir. Başka bir deyişle İslama göre rükünleri ve sıhhat şartları belirtilmiş bir tür nikah vardır.

from functionalist theory, like Turkey Family Structure Research (2010)[24]. In the report of this research, family is fictionalised as “critical significance for strengthening social cohesion and solidarity.”

> T.C. In Article 41 of the Constitution, the family is considered to be society-based and emphasizes that the state must take urgent measures for the peace and well-being of the family. In the 10th Development Plan prepared for the period of 2014-2018 by the Ministry of Development, "the family that constitutes the core of the society and keeps the individuals and the society together is the basic element of being a strong society, individuals who grow up within the framework of tolerance, love and mutual understanding". It is emphasized that the family has a "critical significance for strengthening social cohesion and solidarity". It is also stated in the 10th Development Plan (Ministry of Development, 2013) that "the transition from a wide family to a nuclear family has continued" and that the relations between family members have changed, and in particular, "the increase in divorce rates has resulted in the disintegration of the problems of single- The need for monitoring and guidance is emphasized". In this context, it is stated that family counseling and mediation mechanisms will be developed in order to reduce divorce rates.[25]

The functionalist approach makes it legitimate to intervene in cases which the family structure is endangered, as it constructs the family as a necessary entity for the whole body's proper functioning. In the act of "intervention", there is always an aim: the purpose of taking something from one place and locating it in another place. We can approach this concept as naive as we want, we can reveal its problematic side, but we cannot completely refuse it. The intervention extends from

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[24] Türkiye Aile Yapısı Araştırması (2010)

[25] Translated into English from original: 10. T.C. Anayasası’nın 41. maddesinde aile, toplumun temeli olarak kabul edilmekte ve devletin, ailenin huzur ve refahı için gereli tedbirleri alması gerektiği vurgulanmaktadır. Kalkınma Bakanlığı tarafından 2014-2018 dönemi için hazırlanan 10. Kalkınma Planı’nda *“toplumun çekirdeğini oluşturan, bireyleri ve toplumu bir arada tutan aile kurumu, hoşgörü, sevgi ve karşılıklı anlayış çerçevesinde yetişen bireyler, güçlü toplum olmanın temel esasıdır”* denilerek, ailenin *“toplumsal yapının ve dayanışma- nın güçlendirilmesi için kritik bir öneme sahip”* olduğu vurgulanmaktadır. Yine 10. Kalkınma Planı’nda (Kalkınma Bakanlığı, 2013), ülkemizde *“geniş aileden çekirdek aileye doğru bir geçişin sürdüğü”* ve aile üyeleri arasındaki ilişki biçimlerinin de değiştiği belirtilerek özellikle *“boşanma hızlarındaki artış sonucu oluşan tek ebeveynli ailelerin sorunlarının çözümüne yönelik izleme ve rehberlik ihtiyacının bulunduğu”* vurgulanmaktadır. Bu kapsamda ayrıca, boşanmaların azaltılması amacıyla aile danışmanlığı ve uzlaştırma mekanizmaları geliştirileceği belirtilmektedir. (sayfa: 52)

its most acceptable form as educational practice to the biopolitics that is regarded as the most problematic. The "development paradigm" of psychology or cultural psychology is also compatible with the idea of intervention. Even if the child and the family are not going anywhere at all, they have to develop to some point, which they adapt to the "basic social values" they produce and transmit. Assuming that there is a problem in the family, the process of identifying this problem and seeking a probing solution requires the presence of a "healthy" family model. This definition of the representations of the individuals in the family (the dependency between the mother and the child, the heterosexual love between the mother and the father, and the reciprocal relationship between the family and culture and values) is determined in advance and through this "family situation" that is expected to be achieved as a result of intervention.

What makes this intervention legitimate? Why do the ideas of "structural sameness" work so well in spite of the clear differences between cultures? Who / what produces these sameness? How do the ideas that build a model circulate? Perhaps the first typology example of how personality was shaped was the idea in ancient Greece that "the four humors” that shaped the personality of human person were body fluid (black bile, yellow bile, blood and sputum) (Lonner, 2009, p: 22). Today, debates continue about how much genetics and cultures play a role in personality. Interestingly enough, psychologists, who usually study human cognitive abilities, are working on this area of work that is acceptable to people and perhaps offers comforting ideas. Discussing the long and arduous debate about what human nature is and what humanity brings through birth with such a "given" way leads to the problematizations of both personality and the modern family (the parent-child roles within this family). For this reason, this thesis deals with what is normal, what constitutes normal, what normal includes and excludes by what kind of discourse and representation. Rational interventions appropriate to human nature create a space in which no one can easily go out or contemplate the opposite.

The discussion of "values", one of the most important pillars of Çiğdem Kağıtçıbaşı’s “The Value of Children” research, which is examined in detail in this section, is also crucial for this study. It is necessary to think about the values in order to understand how the normality is established and how the values become a reason to normalize the discourse.

> Schwartz and Bilsky (1987, 1990) generated a conceptual definition of values that incorporates the five formal features of values recurrently mentioned in the literature. This overview is necessarily brief. Values (1) are concepts or beliefs, (2) pertain to desirable end states or behaviors, (3) transcend specific situations, (4) guide selection or evaluation of behavior and events, and (5) are ordered by relative importance. Values, understood this way, differ from attitudes primarily in their generality or abstractness (feature 3) and in their hierarchical ordering by importance (feature 5) (Schwartz, 1992, p:3)

I do not assert that this definiton of value is completely true or valid. Most social scientists who examine the field of value cannot dare to answer with a template theory like the one above, about a field that will lead us to ethical and moral debates which concern what is right, what is good, what is bad, what is desired. Bringing the concept of value out of the individual field into the field of discourse and tracing it culturally can be an important achievement. In this study, the values are scrutinized through the examination of cultural values that are attributed to the family and the child which Çiğdem Kağıtçıbaşı addressed in her research, instead of considering them in the context of universal value.

> These findings point to the home-bound role of women and their dependent status vis-a-vis their husbands. Men tended to accord more importance than women to values implying social recognition, such as achievement or success, being accepted by others, and, more traditionally, continuation of the family name and being remembered after death. The latter two values have implications for fertility because of their association with preference for sons. Finally, financial security ranked high in importance for both sexes, especially for the men. This finding was not surprising, for men are considered responsible for the financial well-being of the family. Thus, through respond- ents' first and second choices of general life values, different patterns emerged for women and men. These subjective values appeared to reflect the generally different life styles, outlooks, and roles of the two sexes. (Kağıtçıbaşı, 1982, p:25)

Needless to say, Kağıtçıbaşı's findings about Turkish families are more comprehensive than mentioned above. This quote can be considered as a sample of how Kağıtçıbaşı conceptualizes the value of families and their members. It is addressed again in the related chapter on how Kağtçıbaşı restricts her discussion of values and the wider evaluation of the findings of her research. A brief discussion of the values here is the reasoning that standing against the intervention is relatively challengingif there are values in question, and it is tracing the normalization based on "cultural values".

Radical discourses find their representations in society faster. “In the visit of the provinces of Afyonkarahisar, Environment and Forestry Minister Veysel Eroğlu said that the high speed train will reach İzmir and Antalya after Eskişehir. Eroğlu answered a woman who wanted a job from him by asking, ‘Is there not enough work at home?’”[26] (Hürriyet, 12 Mart 2009) "Do you know why the unemployment rate is rising? Because more people are searching job in times of crisis, the participation rate in the workforce is increasing during the crisis period, especially among the women" said Government Minister Mehmet Şimşek.[27] (Bianet, 20 Mart 2009)

> Beautiful books are released. There are beautiful books that people can carry in their pockets and put them in their bags. We need to rediscover the Koran. There is a collapse in morality. Modesty is very important; modesty, and shame. 'When you look at her/his face and if her/his face is blushing' Hadith-i Sharif says so, modesty is beautiful. It is even more beautiful if it is female. There is a thing called modesty for all creatures, not just for women but for men. It is a good thing also for men. He can not lie, he will not say a word of embarrassment, he will drop his head. Where are our daughters who when we look at their face, their faces blush slightly, they will escape their eyes from our eyes, they are the symbol of chastity? Chastity is very important. It's not just a name. Chastity is an ornament for women. It's also an ornament for men. Women must be chaste. Men must be either, not a lecher. They must be loyal to their partner. They must love their children. If she is a woman she must be chaste, too. She should be able to seperate what is confidental and what is not. She should not laugh to everyone. You should not be attractive in all of your movements, you shall protect your chastity. Now, when somebody says this, they can say, 'What kind of langaugae is this?' Today, we are so alienated to our values. "[28] (Radikal, 28 Temmuz 2014)

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[26] http://www.hurriyet.com.tr/bakan-eroglundan-is-isteyen-kadina-garip-cevap-11196061

[27] http://bianet.org/bianet/emek/113282-bakan-simsek-ten-issizlige-cozum-haydi-kadinlar-eve

[28] Translated English from original: “Çok güzel kitaplar çıkıyor. İnsanın cebinde taşıyabileceği, çantasına koyabileceği çok güzel kitaplar çıkıyor. Kuran'ı yeniden keşfetmemiz lazım. Ahlaken bir

Vice Prime Minister Bülent Arınç focused on "values" and how men and especially woman must behave according to these values. This is basically why I assume as the related issues the interfering discourses and values. I assert here that values make the discourses of the power and the forms of intervention that I mentioned above more "invisible" and "proper the society." *Cultural appropriateness* can be considered as a crucial notion for the process of tracing what functions as the "normal" in society. Ableism does not consider that it causes the "evil" with the idea it brings. There is an image of being healty, being agreed to norms, and being "normal". Secondly, -maybe there is not a hierarchy between these steps- there is a decision of who can take a position in this imagination or who cannot. In other words, the wheels start turning to determine who will be included in this area and who stays outside. For the very reason, the interventions that aim retrieving the "deviated" one to this area can be regarded as necessary sanctions for order and decent functioning of the society. "For an intervention to be successful, there must be a causal link between a change in the target (or changes in multiple targets) and a change in the outcome (or changes in multiple outcomes). Thus, a culturally appropriate intervention must be thought of as one that would facilitate the operation of this causal process in a given socio-cultural context." (Baydar, 2009, p: 315)

The inevitability and inclusiveness of normal is also due to the legitimate ground on which it is based. For instance, if somebody declares that women should not work, they have to stay at home and their only business must be domestic work,

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geriye gidiş var. Haya meselesi çok önemlidir. Haya, utanma duygusu. 'Yüzüne baktığın zaman yüzü kızarıyorsa' Hadis-i Şerif öyle diyor, haya güzeldir. Kadında olsa daha da güzeldir. Sadece kadın için değil erkek için bütün mahlukat için haya diye bir şey var. Erkekler için de haya vardır. Yalan söyleyemez, mahcubiyet ifade edecek bir söz söylemeye kalksa yüzünü yere bakar. Nerede öyle yüzüne baktığımız zaman yüzü hafifçe kızarabilecek, boynunu öne eğebilecek, gözünü bizden kaçırabilecek iffet sembolü haya sembolü kızlarımız. İffet çok önemli. Sadece bir isim değil. Kadın için de bir süstür, iffet. Erkek için de bir süstür. İffetli olacak. Erkek de olacak. Zampara olmayacak. Eşine bağlı olacak. Çocuklarını sevecek. Kadın ise o da iffetli olacak. Mahrem-namahrem bilecek. Herkesin içerisinde kahkaha atmayacak. Bütün hareketlerinde cazibedar olmayacak, iffetini koruyacaksın. Şimdi bunu birileri söylediği zaman 'ya bu adam hangi dilden konuşuyor' diyebilirler. Bu kadar değerlerimize yabancılaştık bugün ."
http://www.radikal.com.tr/politika/arinc-kadin-herkesin-icinde-kahkaha-atmayacak-1204217/

this statement creates a profound crack. However, when somebody says that the child must be taken care of by his/her mother, different groups from every class and cultural structure of society easily adopt this argument.[29] The main reason for the examination of the relations between intervention, culture and values is that the intervention to the family and to disability itself is regarded as "normal". How the family is established is defined as a structure in which the distribution of roles is predetermined and exists through certain values. This narrative, produced through power and representations on the family, enables to identify deviations and interventions on family. Disability is visible through an impairment body, which, at first, should be rehabilitated by medicine. Here, it is investigated how the disability creates a break between the "normal" family and "healthy" child narrative, and how this experience displays the power and the ableist approach to society.

2.3.2. A Research by Çiğdem Kağıtçıbaşı: "The Changing Value of Children in Turkey"

Cultural psychology, which mostly examines the socialization process of a human being as an "individual of society" with the concepts of "development and change", regarded the family as one of the basic structures producing the child - both biologically and culturally.

Çiğdem Kağıtçıbaşı, who has studied the field of cultural psychology for many years, suggested the "Model of Family Change" which is developed as a result of various field investigations and theoretical background. Kağıtçıbaşı's model of family categorizes Turkish families according to their rurality-urbanism, and offers that this cultural difference determines the shape and dose of the

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[29] Actor Cem Davran wrote on Twitter: "The mother should raise her child, and should leave career plans aside". It is possible to say that he took support on Twitter and *Ekşi Sözlük* for his idea about mothers. (link: https://eksisozluk.com/cocugu-anne-buyutur-birakin-su-kariyer-tribini--4995936)

psychological-economic dependencies of the families. No wonder, this definition of model is extremely rough because Kağıtçıbaşı carried out this research approximately twenty years with revisions and refinements (Nauck, 2009, p: 212). Originally, Kağıtçıbaşı created her Model of Family Change in order to analize the data of her Value of Children research (Kağıtçıbaşı, 1982). However, later the model became one of the most extensive field surveys in Turkey with the contributions of Bilge Ataca who is a student of Kağıtçıbaşı (Ataca and Kağıtçıbaşı, 2005).

> Three prototypical family patterns were distinguished. The first, the “family model of interdependence”, is more common in less developed, rural, agrarian contexts with closely knit human ties (“cultures of relatedness” or collectivism) and is characterised by familial interdependencies in both psychological and material realms. The contrasting pattern of “independence” is more common in Western industrial urban settings with an individualistic culture. A third pattern, the “model of psychological (emotional) interdependence”, is a synthesis of the first two patterns and is posited to characterise the urban and more developed socioeconomic contexts with cultures of relatedness, rather than a shift from the pattern of interdependence to that of independence with social change and development. This is evidenced by VOC findings and other research that points to the continuation, even increase, of emotional dependencies with socioeconomic development while material dependencies decrease (Ataca & Sunar, 1999; Duben, 1982; Erelcin, 1988; Imamoglu, 1987; Yang, 1988). (Ataca and Kağıtçıbaşı, 2005, p: 319)

Classification of family by Kağıtçıbaşı can be considered as an example of "horizontal historical reading" in the first place. It can be argued that it contains an idea of progress related to modernization. However, she pointed out that there will be multiple endpoints and a multifaceted change in her work. “In countries like Turkey, familial and social interactions are characterized by close interpersonal ties and interdependence. Even through family nucleation, this type of human interaction continues, penetrating into the “modern” family pattern.” (Kağıtçıbaşı, 1985) In extended version of Model of Family Change, Kağıtçıbaşı regards a multiple relationship “agency” and “interpersonel distance” and mentioned four family model: There are “independence”, “psychological interdependence”, “interdepedence” and “hierarchical neglect.” (Nauck, 2009, p: 213).

Indeed, Kağıtçıbaşı's the Value of Children research is so complicated and stratified that it cannot be briefly presented. I try to summarize her findings and interpretations according to this thesis impliements about the families with disabled child and their positions in an "ableist" society. Therefore, this struggle of summarisation can proceed with quaotes from her output text of research. In the summary version, in English (the Changing Value of Children in Turkey), Kağıtçıbaşı starts the text with this sentence, "The main objective of the study was to increase understanding of the place and role of children in the Turkish family and society" (Kağıtçıbaşı, 1982).

VOC was a worldwide research including Indonesia, the Republic of Korea, the Philippines, Singapore, Taiwan, Turkey, the United States, and subsequently the Federal Republic of Germany. The questions of survey were adaptedto Turkey. The research questions were prepared in two separate forms for couples with and without children. The topics of questions were desired number of children, ideal number of children, values and costs of children, number and sex preferences, ideas about "quality" children, general values, financial expectations from children, birth control (attitudes, knowledge, and use), decision context (belief in internal versus external control of reinforcement), sex roles, education and occupation, mobility, mass media exposure, family type, and income (Kağıtçıbaşı, 1982).

Eighty-five interviewers selected by a screening committee for the project were given a ten-day training in August 1975. "About three-fourths of the interviewers were chosen from among women candidates to interview women respondents, who formed three-fourths of the sample." Interviewers were preferred in order not to have too big of an age difference between interviewers and respondents. (Kağıtçıbaşı, 1982, p: 8). Respondents were selected from 67 provinces of Turkey and divided into three strata according to their level of socioeconomic development 1) most developed, (2) intermediate, and (3) least developed. The Turkish sample consisted of 2,305 respondents of whom 1,762 were women and 543 were men. Istanbul, Ankara, and Izmir are considered highly developed. "The grouping of provinces was based on the geometric mean of ranks on various social and economic variables. Provinces with a mean rank of between 1 and 20 were considered most developed, those with a mean between 21 and 40 were considered intermediate, and those with a mean above 40 were considered least developed." (ibid, pp: 9, 10) Kağıtçıbaşı separates various subgroups to examine the characteristics of respondents. These were current age and age at marriage, education, occupation, income, family type and mobility, actual, desired and ideal number of children, basic values and sex roles.

This comperehensive fieldwork had some hypotheses in the begining. I quote them here, because these hypoteses are crucial to determine the assumptions about families in Turkey.

> 1. Values attributed to children are varied and are of three types: psychological, economic or utilitarian, and social or normative.
>
> 2. Costs attributed to children are varied and are of three types: psychological, economic, and social.
>
> 3. With socioeconomic development, the types of value attributed to children change. Specifically, as level of development and individual socioeconomic status increase (as indicated by increased education, income, occupation level, development level of area of residence, urbanism, and rural-to-urban mobility), the economic/utilitarian value of children loses importance, and their psychological value gains importance.
>
> 4. With socioeconomic development of an area and increased socioeconomic status of couples, the opportunity cost of children increases.
>
> 5. As a couple's parity increases, the economic/utilitarian value of their children increases and the psychological value decreases.
>
> 6. As parity increases, the economic cost of children increases and the opportunity cost decreases.
>
> 7. Values attributed to sons are different from those attributed to daughters, the economic value of the sons assuming importance.
>
> 8. As communication between spouses, role sharing, and decision sharing increase (i.e., as a woman's status within the family in- creases), the economic/utilitarian value of children and boy preference decrease and the psychological value of children in- creases.

> 9. Values of children explain some of the variance in couples' fertility even when socioeconomic development variables are con- trolled. Specifically, the economic/utilitarian value of children is a predictor of high fertility and the psychological value is a predictor of low fertility. Boy preference is also a predictor of high fertility.
>
> 10. As communication between spouses, role sharing, and decision sharing increase, fertility decreases.
>
> 11. As level of development and socioeconomic status increase, fertility decreases. (ibid, pp: 31,32,33)

"Help from children", "benefit for family, the God and the country", "benefit for the marriage", "social acceptance", "children as companions/fun", "living through children", "character, fulfillment, experience" were the main categories of the results of the investigation which revealed the value of the child. When Kağıtçıbaşı examines the findings, she forms a category as "costs of children". These are "economic costs", "emotional/physical costs", "upbringing problems", "restriction of parent's freedom", "social problems" (Kağıtçıbaşı, 1982).

> The VOC findings pointed to different types of values attributed to children and showed that these different values were differentialy affected by economic development. Three different types of values were found in the original study, namely, economic/utilitarian, psychological, and social. The economic/ utilitarian values include children's material benefits to their families while they are young in the form of contribution to household economy and household chores, and also old-age security for parents when they grow up to be adults. The psychological value of the child refers to the psycohological benefits of having children, *such as the joy, fun, companionship, pride and sense of accomplishment that children give to their parents*. Finally, the social VOC has to do with the *social acceptance people enjoy when they have children*. (Ataca, 2009, p: 109)[30]

We can find detailed charts about findings of VOC research, however, one

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[30] Emphasis mine

of the fundamental findings of the first VOC research “based on crosssectional comparisons was related to the socio-economic development, and especially with increased education, children’s economic/utilitarian value decreased” (Ataca, 2009, p: 109). The psychological and social values of the child increased in responseto the “development” and “modernization”. Although Kağıtçıbaşı has determined the socio-economic level of the family as one of the main divisions of the research, she also discussed the findings of the research with respect to the concept of “gender.” According to Kağıtçıbaşı’s conceptualization of modernization, is co-ordinated with the increase in the level of women's role distribution in family and the increase in the level of education. As paid regard to hypothesis, womens’ status in family has an important role in evaluation of findings and Kağıtçıbaşı compares research findings with hypothesis, and the research findings reveal that the findings are consistent with the hypotheses except for a few intricate cases. Kağıtçıbaşı also determines that this study can provide an explanation of the decline in fertility behavior and the findings of research have a political possibility.

The research can be criticized at first sight of being structuralist and supporting the modernity paradigm. However, it should be acknowledged that in Turkey there is no more comprehensive investigation about the values of families and the value of the child. Therefore, this study is crucial for this thesis because of the fact that it has the courage to embody value. As Kağıtçıbaşı points out in the beginning of her research, the child's value has both an individual and a social dimension, and we cannot deny the significance of the perception of “normal" for this value. As explained below in more detail, the value of disabled child recreates the value of the child's narrative.

2.4. A FRACTURE IN THE "VALUE OF CHILD": HAVING A DISABLED CHILD

"You are one birth away from my experience,

that's what I think…"

Nancy Melzer

> Sadness, grief, guilt and isolation are feelings parents described when they were told their child was "mentally retarded." The strange names for the diagnosis –mongolism, infantile schizoprhrenia, brain damage, spactic- were unknown them. They turned to their doctors, pediatricians, and religious leaders for help only to learn that they too knew very little. Information was scant, contradictory and often inaccurate. Based on "disreputable" research, mothers were blamed for their child's condition. The "prescription" most parents were given was to institutionalize. To forget about this child and have another. (Schwartzenberg, 2005, p:3)

As I mentioned before, when I decided to write this thesis, I was disappointed by the fact that there are few studies on the relationship between the family and their disabled children in Turkish social sciences literature. The investigations were in the field of either medicine or psychology at best, and were shaped on the "negative" impact of the disabled child on the family. This view sharply restrained the opportunity of problematizing the norms of society, the definition of the family, the originality of the experiences, and the idea of who should "fix" according the normal of the society.

According to Siegel and Siverstein who conducted more researches on the families who have a child with autism spectrum disorder, families with disabled children experience the feeling of losing a "perfect" child, and this resembles the feeling of *grief* experienced by the loss of a loved one (Siegel and Siverstein, 2001).

This definition is important because one of the aims of this research is to investigate how social norms determine the idea of perfect child.

Moreover, the number of studies which focus on the families with disabled child through the analysis of emotions and experiences were very few to be tried. The nuclear (normal) family, as I have attempted to explain throughout the second chapter, was treated as a functional organ which "produce" child, and "integrate" her/him into the society to safeguard the continuity of society's norms. It was legitimate for the government to take various precautions and to organize intervention models at the point where it was supposed that the settled function of the family is dissolving. Normal not just determined who was going to stay inside or outside, but it had to be consistently reproduced at the same time. In this case, the family is influenced by social norms and it is also positioned inside the main producers of norms. “The language often used to refer to kinship, intimacy, and domestic sharing is monolithic: “The family” implies a firm, unchanging entity, always similar in shape and content” (Thorne, 1992, p:6) Special (nuclear) bonds, private space (home) and heterosexual love are three concepts that are referred usually when somebody wants to conceptualize the nuclear family. This stereotypical and constructivist view of the family creates a question about the functioning of the families with disabled children, and it seems possible to be acted as an exclusionist mechanism in this way. Whene one of the most basic functions of the family is defined as raising "healthy" children for society, a crisis of function emerges for the families with disabled children.

“Turkish households (including rural) are in general nuclear in structure (Berik 1995, Delaney, 1991; Starr 1989; Timur 1972). However, nuclear families *function* like extended families, with close social ties, much social support and interaction among close relatives, who also close to each other.” (Ataca, 2009, p: 111) Emotional bonds and social contacts of the families make them “functionally extended.” Knowing how the family functions specifically in Turkey can make it easier to trace the potential support or exclusion mechanisms that the families with disabled child confront, although it is objectionable since it only provides a general idea about the role of the family in Turkish society. In this thesis, sentiments of the families with respect to the support and exclusion that they received are examined through the narratives of the families with the disabled child.

Indeed, my main purpose was not to make a comprehensive and diverse analysis of families in Turkey. How the normal and normal/nuclear family were established through the representations and implicit values in these representations and how a family which has a disabled child experiences this normalcy were the two bearings of this study. Hereafter, I attempt to explain why Çiğdem Kağıtçıbaşı's Value of Children research was one of the inspiration ideas of this thesis.

Çiğdem Kağıtçıbaşı's Value of Children research has been recently replicated in Turkey (2005). Three generations from middle/upper, middle and lower socio- economic strata who live in two rural areas in Turkey- eastern and western provinces- one metropolitan center (Istanbul) participated in the research. The research focused on the change which took place in the last thirty years, the significant decrease in the economic/utilitarian value of the child and the remarkable increase in psychological value (Ataca, 2009).

"The values attributed to children by parents reflect both the needs of the parents and the place of children in the family and society." (Kağıtçıbaşı, 1982, p: 33) Why do the parents of disabled children feel sadness, grief, guilt and isolation? Findings of Kağıtçıbaşı's VOC resaearch may shed light on this question. By paticipants the values (advantages) of child ranges as help in housework, help in old age, financial and practical help, to maintain family name/ family line, religious and social obligations, benefits for marital bond and home life, to enable accepting in adult status and social norms, getting companionship, love, avoidance of loneliness, happiness, fun at home, amusement, living through children, achievement, power, incentive to succeed, fulfillment. (Ibid, p: 34) As we can easily notice with an overall look, the above valuesmentioned are related to exist in the society and they are built on certain future expectations.

If we analyze the findings of the research about costs (disadvantages) of child, the answers include these topics: cost of education, general financial costs, more work, emotional stress, responsibility, effects on health, appearence, pregnancy, fear of abnormal birth, discipline, sickness, worry about child's future, tied down, can't work, marital strains, overpopulation (Ibid, p: 39). As a result, we can think that the disabled child is almost the only reason of these "costs" for the family. On the contrary, if everything works well to the fantasy, a "healthy" child gives you the great experience of having a child. Is it really so in real life?

Lassetter, Mandleco and Roper, who suggested to take photos of the families with disabled children, which , aim to explore and record important moments from the daily lives of those families. Thereafter, the researchers asked the participants thje reason why they took those photos and their feelings about the photos. Fifteen parental dyads raising a child with Down Syndrome, developmental disabilities, visual impairments, or speech disorders participated in the research. "Four themes emerged from content analysis of the photos: active activities, quiet activities, activ- ities of daily living, and care of the child with a disability. Six themes emerged when discussing photographs participants would have liked to take but did not. These themes were acceptance, concern for the future, joys, struggles, balance of good and bad times, and normalcy" (Lassater, Mandleco, Roper, 2007, p: 458). One of the most significant findings of the research was that most participants did not see their lives much different from the parents who raised their children without disabilities.

> Societies like the United States tend to relegate members of society who are defined as having a disability (or disabilities) to the private realm – that is, the realm of the family. Disability, by default, then becomes a personal and family "problem." When disabilities cause individuals to be unable to fulfill their basic needs, our first instinct is to expect family members to provide special care. When there are barriers to disabled individuals' health care, paid work, or mobility, it is also often family members who are expected to pick up the slack… Ideas within the literature on disability studies can be useful in expanding how we conceptualize familial experiences and think about how families negotiate disability or impairment. Disability scholars teach us to 'separat[e] out "impairment" (that is, the functional limitations of our bodies and minds, or the actual physical or cognitive "disabilities") from the subjectivity of "disability" (that is, the attitudes towards disability or the structural barriers that a disabled person might face in society) (Morris, 2001, p. 2). Hughes and Patterson (1997) and Thomas (1999) further remind us that we need to pay attention to the embodied experiences of impairment, while also paying attention to the social barriers, new

> relations and interactions, and personal experiences associated with physical or cognitive impairment. (Dillaway and Haskin, 2013, p:i)

Ignoring subjective experiences, leaving the disabled child and their families out of the public sphere and forcing them to remain in private space may be functional for reproducting normal, but not realistic situations. As elaborately argued in previous chapters, the possibilities of bodies are different for various situations and it is not a solution to consider the disabled individuals and their experiences under the category of "normal". Hence, in this thesis, if it seems inadequate, a field research was required. It is asked to the parents what they feel when they learned that they have a disabled child, and whether these feelings changed during the growth process of their children, and all the participants answered this question positively and they shared their experiences.

There is one theoretical concept I would like to talk about before the experiences of the parents. “The notion of motherhood gains new meanings through modern changes while preserving its traditional references. It has, however, a content which categorizes women as “mothers vs. others” and it is oppressive not only to mothers but also to childfree women. The discourse of “ideal mother” creates many dichotomies and these dichotomies affect all women.” (Sever, 2015, p: 72) When it is considered as an ideal type of presentation of family and women, motherhood is a position of social production which often emphasizes. I intentionally call it a “production” because the supremacy of motherhood has been produced in everyday life through media, newspapers, movies etc. In Yeşilçam Movies, mothers are “angels”, it is a common replic in Turkey: “Your mother was an angel, sweetheart!”.[31] When the idea that the woman can only be complete after being a mother. When motherhood is the subject a "feminine substance" is underlined makes the arguments about mother more inevitable and inclusive. The adjectives of “childless” and “childfree” given to women which are mentioned by

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[31] For more detailed reading: İş, Sema Merve, *Tracking the Invisible: Queer Approaches to Parenthood and Family in Turkey*, Unpublished Master Thesis, Sabancı University.

Elisabeth Badinter, points to a situation when women voluntarily do not have children, which withdraws them from the normal of society (Badinter, 2011).

This view that regards as equal to motherhood and woman becomes even more pronounced and inclusive when it comes to being the mother of a disabled child. Combining with invisible labor of woman and gender roles to become the "enduring" even "suffering" mother. This perception, which is easily encountered in Turkey's newspaper reports and considered not often as problematic, leads us to think that the care of the disabled child is the job of the women.[32] It was also noticed during fieldwork that mothers could easily convert from the "angel mother" to the "guilty mother". Some of the interviewers, stated that this accusation is valid for themselves and the other mothers they see in their surroundings.

CHAPTER 3

RESEARCH METODOLOGY

Long before I started to write this thesis, I had some concerns about the “nature of researching”. The researchs which traces the notions and their historicalness are thought more acceptable by the new approaches of social science[33]. Field researches are assumed to contain a handicap. The handicap that I mean is “intervention”. In the second part of this thesis I have tried to demonstrate how the values and “normal” of society legitimize the intervention.

Despite all the risks of field research, I think it is a crucial to share distinctive experiences. The importance of the theorotical framework cannot be denied either. When I decided to analyze the subject of disability, I realized that theorotical explanations and notions emerge as a response to the experiences of

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[32] http://www.yeniakit.com.tr/haber/cefakar-annenin-tek-istegi-tekerlekli-sandalye-326582.html

[33] I refere here to “poststructuralist approaches”.

disabled people and their rights. It is not possible to ignore the contribution of the disabled scholars to the theoretical field. It should be noted that this work has been endeavored to bring the theory and practice together.

After I questioned the concept of subjectivity many times, I realized even the most subjective cases include a social side. As a person who does not seem disabled, as my body fits in symbolic systems and normal of society, the method itself was as important as the courage to investigate the issue of disability.

I decided to conduct a field research and to have interviews with families with disabled children. My main activity was to listen to the families' experiences, emotions, and opinions about having disabled children, society, norms and the relationship between these concepts. I prepared nine questions[34] that situate basically around how the families feel when they learn their child is disabled, how the others and society react to it and whether their feelings/emotions/opinions change in the process of raising their child. While determining the families for interviews the distinction was not made according to the types of their children's disabilities as physical or intellectual. Such a distinction would mean accepting the mind/body dualism in the thesis. Besides, the interviews proceeded through open-ended questions in semi-structured form. Each interview lasted approximately an hour. In the beginning of the interviews, the families were not asked direct questions about education levels, ages, income or elobareted informations of their children. Interviewees provided this information in a conversation which was trigged by other questions. My intention was to observe the relationships which they have created rather than getting the necessary information quickly. Nevertheless, it is possible to say that more information appeared than expected during the interviews.

Seven mothers and only one father were interviewed. Five of them were the parent of a child who is with "cerebral palsy" which is refered to as "being spastic" by the public. "While Cerebral Palsy (pronounced seh-ree-brel pawl-zee) is a blanket term commonly referred to as "CP" and described by loss or impairment of motor function, Cerebral Palsy is actually caused by brain damage. The brain

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[34] It can be founded in "APPENDİX"

damage is caused by brain injury or abnormal development of the brain that occurs while a child's brain is still developing — before birth, during birth, or immediately after birth." Cerebral Palsy is commonly regarded as a physical disability which affects body movement, muscle control, muscle coordination, muscle tone, reflex, posture and balance and it can also affect fine motor skills, gross motor skills and oral motor functioning.[35]

Last summer, when I was a volunteer in "Dreams Academy/Kaş" which is a place that organizes sport and art programmes for different ranges of disabilities, I realized that CP can easily uncover the biases of society. When somebody faces a person with CP for the first time and you realize the impaired body and the situation arises from impairment –such as difficulty of speaking- the first reaction is that the voice rises as if you speak with someone with a "foreigner". Although a person with the CP usually has the same intellectual awareness as his or her peers, the words start to be spoken separately or even if you do not understand what they say, instead of asking you do not understand them and repeat again, you tend to pretend that you understand. Although medicine tries to position physical disability and intellectual disability apart from each other, CP seems to be a good example to understand how the two are intertwined in social area.

I hope that such a comprehensive and detailed presentation of the CP does not cause any misunderstanding because I have observed that there are individual/distinctive experiences of each participant even if their children have the same kind of disability. The circumstances shared by their experiences were coming into when they contact with the society. This finding can be regarded as one of the most crucial outputs of the field research.

The interviewees were Suna *Hanım* who is the mother of twin sons with visual impairment, Gülser *Hanım* who is the mother of five children and the youngest of which has Down Syndrome, İbrahim *Bey* who is the father of one son with CP, Yersu *Hanım* who is the mother of two children, the older one with CP and the youngest one is still a baby, İstemihan *Hanım* who has one son with CP,

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[35] http://www.cerebralpalsy.org/about-cerebral-palsy/definition

Nilay *Hanım* who has one son with CP and one daughter, Fadime *Hanım* who has one son with *epidermolizis bulloza* from birth and he has also *ostogenezis impervekta* and Sinem Hanım who has triplet daughters with CP.

It should also be mentioned that the parents who were interviewed has connections with different associations and foundations in an active or passive way. Suna *Hanım* (Parıltı Derneği), Gülser Hanım (Tomurcuk Kooperatifi), Yersu Hanım, İbrahim Bey, İstemihan Hanım and Sinem Hanım (SERÇEV- Serebral Palsili Çocuklar Derneği) and Fadime Hanım (TOFD- Omurilik Felçlileri Derneği) have active bonds with the associations that are related to their childrens' disabilities. Nilay Hanım told that she used to be the member of an association but now she belongs to a different support group.

When I started to analyze the data, I was not comfortable with discussing the interviwees separately under the concepts I chose, searched, and defined. In the previous sections of the thesis, the concept of "normal", disability theories and the concepts about the family were discussed. Çiğdem Kağıtçıbaşı's "Value of Children" research gave this thesis an idea of how the parents who live in Turkey look at the child's social and individual existence. This fieldwork was based on exploring the parents' experiences of both the public and private spaces. For this reason, the questions asked to the family were selected from the three areas mentioned above- what they felt when learn their child's disability, whether their feelings/ emotions/opinions changed in the process of raising their child, how they feel now, how the others and society react to their childrens' disability. I have decided to classify the outputs of the interviews under these three titles

CHAPTER 4

RESULTS

4.1. FINDINGS

4.1.1. Feelings in the First Place

The narratives gathered under this title demonstrate what the parents felt/thought when they learned that their child is disabled. As it can be easily found in the following explanations, first emotions that the families had were “desperation” and “helplessness”. It can be said that the reason why the Value of Child research is regarded as the main bearing of this study is indicated in these narratives. In this study, it is alleged that the concerns of parents about the functioning of "healthy" children create an imagination of and expectation from the child.

Indeed, it is possible to interpret that this narrative of the "healthy" child is formed in a multifaceted way, and possibly that is why it is so extensive. The child is raised both with a function of the present existence at home and a dream and expectation of the future. Moreover, this functionality and expectations are not only related to one area. The child's presence has a sharp impact both on the private space and the public space. As the research of Çiğdem Kağıtçıbaşı reveals, the discourse about the "values" of the children is built on “fullfillment” at home within the society and in the future. It is not difficult to understand why a family has a feeling of *deprivation* when they learn that they have a disabled child, given the normal child's narrative in society.

Suna *Hanım* who is the mother of twin children born with undeveloped eye corneas due to premature birth told that

> It is a very difficult process to accept, the mother may accept it easier than fathers, but the fathers always stand apart or do not want to admit it. However, my husband, my mother and my father were always with me, they supported us, they never left us alone in aspects of sociability, education, in everything. First, they have trusted in me because I have always met good people thanks to Allah with those who show always the right way like Hale Bacakoğlu, the current president of the association.

İbrahim *Bey,* whose son has Cerebral Palsy, said,

> Efe was a very small and fragile baby and we thought if Efe will live before he is disabled. I was very upset when I learned that he is disabled. Her mother was very sad also but she was less unhappy than me. Her first priority was the child's momentary and daily needs, and then I remember that I had difficulty to accept it. So Efe's mother told me that his diaper needed to be changed, he needed blood transfusions or the doctors would take an x-ray. While she was dealing with them, I was far ahead, thinking about what would happen when he starts to go the school, when he searches a job. There was a very serious difference in medicine. One day, however, doctors said that we have a chance not to accept the treatment. I said, what does that mean? They said that some people do not want to use medication, do not want their children to be connected to the breathing apparatus. I said no, if there is any possibility in medicine, you will do all of them, so I assessed and closed this issue up. After that, we continued to deal with daily necessities rather than disability.

The fieldwork, also focused on how gender affects the feelings of the parents who have disabled child and how the relationship is established. Thus, the question "How did your wife/husband feel, think, and behave?" was also added. However, it was observed that most of the answers about gender came spontaneously without asking any questions. The shared thought was that mothers easily accepted the process. The reason for this was that the mother focused on the child's daily needs. This information is interesting because it suggests that the mother's focus on the child's needs can be related to the relation of mother with her "own child" rather than "an inclusive narrative of the child" and that the father continues to be articulated in the child’s general narrative. Needless to say, as mentioned above, it is evident that the women’s involvement in the child care in the family is related to a social acceptance, and to the women’s' invisible labor. It is differently presented here that a one-to-one relationship established with the disabled child makes it easier to produce this distinctive experience.

Gülser *Hanım* has a daughter with down syndrome, she said that

> the doctors said that she would be disabled, and she needs blood exchange. However, her father objected to it. And after they said that there is a risk of mental deficiency and then, her father gave a permission for blood transfusion. There was a risk of mental deficiency or down syndrome. I was working as a teacher for 21 years, but I had not heard of down syndrome. I have known about mental deficiency but I have never thought about the possibility of happening to my child. I said, oh no, I tried to teach something to children for 21 years but now I will not be able teach my own child. She can never read the books which I suggest her. These kind of ideas came to my mind. I felt fear and anxiety. I could not see the future.

Nilay *Hanım* lost her husband while she was pregnant and her son came to the world with cerebral palsy. She said that she thought she should take *it as a burden* because of people's reactions. She says, "Although for the first two years I had been shocked, later it has become very normal for me. It is normal for my son to be disabled, as it is normal for my daughter to be not disabled."

Yersu *Hanım* who is a mother of two children, of whom the older one has cerebral palsy, defines her emotions/thoughts when she learned that her daughter was born with cerebral palsy as, "Of course we did not know what to do, our world has collapsed. We seemed to be in such a bottomless well, but then, we negotiated by learning all of them. We started to accept him as he is."

"I do not know how I feel when I learned that my child is disabled, but I was very worried when I learned that he was spastic because of the previous information I had about disability." said İstemihan *Hanım* who has one son with cerebral palsy. "I did not know what to do because they did not give me any explanatory information. It's a strange feeling."

Fadime *Hanım* says,

> There was a shock, a sadness, etc. when Kaan was born, but we perceived him as a child with wounds... We did not perceive him as disabled. ... There were sores, there were sores on his feet. We hoped that he would get better. Even the doctor told me not to have a second child. If I want to have a second child, I had to perform tests during pregnancy. At that time, the tests costed around 2000 Euros, we did not have the means... I do not consider having second child. Turkey is not a country for having children. You will bring the child to a world, in which she/he could be healthy. One day he can still ask: if you knew the situation of this country, why did you bring me to the world?

Sinem *Hanım* has triplet daughters with Cerebral Palsy, she explained her situation as,

> My children were triplet, and I learned that my children were disabled when they were one year old. Since they were triplet, an already tough life was waiting for us. We would always need a third person. When I learned first that Büşra is disabled I thought that we could deal with this fact together with her sisters. The idea of disability was not fully settled in my head. Later, when I learned about Tuğba and finally Esra, of course I met a reality beyond the imagination that I created and I was distressed for two years. Then, I realized that the disability was outside, and proceeded by struggling with them, overcoming disabilties, and accepting the process.

Another situation that arises through narratives is how medicine treats disability. Most of the families said that medicine, and therefore doctors, looked at their children with a "disabled/healthy" duality. I expressed in the first part of the thesis, it can be said that this idea around the existence and absence of "impairment" makes it difficult for the families to have knowledge about possible experiences and the other possibilities of life for their children.

Further consequence of the statements is that the doctors think that the authority to make decisions about children belongs to the father. As İbrahim *Bey* and Gülser *Hanım* have noticed, the information about the disability of the child is first shared with the father. This fact also complies with the idea of homogeneity and distribution of predicted roles for the nuclear family.

4.1.2. Sharing the Disability with Others: My Child is Disabled

Although the notions of "normal" and ableism which form one of the main pillars of the thesis have emerged in almost all parts of the narratives, the most productive area to look at is what the family feels, thinks or experiences when they shared their children's disability with their close environments. Accusing the mother of the child's disability, watching the process with a foreign admission, or wanting to partner in the relation with the child were the common reactions revealed in the narratives. Most of the families said that the peoples' unawareness of this experience makes it difficult for them to understand their experience and give support.

Suna *Hanım* says,

> Sometimes I cry and ignore it. We had a period of isolation for the first three months because I had given early birth to my children. No one else could watch the children so I could not leave them alone and go somewhere else. By the way, people have heard of our situation. I heard that my parents are crying. I cry, they cry, but everyone seems to be strong when they are near to me. Everyone pretended that all was good.

Sinem *Hanım* says,

> Everyone looked after me, nobody has excluded us because of my children's disability. My family, my neighbours, my friends... In any case, we did not live complexity of the situation, we have never experienced the sense of exclusion that most families are sorry for.

Suna *Hanım* and Sinem *Hanım* are the mothers who say they received a lot of support from their close surroundings. Furthermore, Suna *Hanım* said that they physically shared the same place with her parents and siblings, and they were living in the same building. On the other hand, Suna Hanım told that both the support of Parıltı Association and her close surroundings helped her.

Another point I want to mention here is that Suna Hanım's children are twins and Sinem Hanım's children are triplets. Sinem Hanım stated that they already knew they would need a third person because their children were triplets. Growth of the solidarity network through organic ways can be affected by the general knowledge of "the need for parental help in multiple births". In a similar way, the daily relationship which the mother has with the child can be considered as a point that breaks the duality of the "disabled child / healthy child".

Gülser *Hanım* says,

> Now look, when you say your environment, let's start with the family, the parents. There is always an infighting about who is responsible for disability. This occurs in every family, either educated or uneducated. It happened because of you or me. They question this issue first. My husband was a lawyer, even he said this child looks like you. I said okay, you or me, does it change the result? Does it change anything for the child, if you blame me or we blame each other? My sister in law also has a disabled child. I said okay, let's just say that this is from me, what causes your sister's disabled child? He said it is because of her husband. I laughed and said that you can talk about it in the family and relax, but do not tell it anyone from outside... Look, there are also families living in cities, and in rural areas. In rural areas, this responsibility remains mostly on the mother's side because they cannot defend themselves. There is also no need to defend themselves, such an understanding exists in society in general as well.

Nilay *Hanım* says,

> My husband's family is more supportive and positive than my family, they wished everything to be good with nice feelings but my family... How can I tell, they were very hopeless, they were sad, they were negatively affected. So, they could not support me. After a while, they even blamed me for failing, they said that I have not taken care of myself when I was pregnant, they mentioned he still cannot walk like others, like his peers. They accused me. Neighbours, friends, the third person, they thought it was a very difficult job and I handled it very well. My closest friends also made great comments. They thought that my behaviour after accepting my situation was very healthy. I do not know, I am raising two children, but I do not treat him differently because he is disabled. They think that I am fair. I have heard a lot of positive things from my close friends lately.

I must admit that at first I never thought that the mother was accused of her child's disability, however, according to the interviewers, who revelead their thoughts about this issue from their own perspectives as well as from their surroundings, this is the case. Moreover, this does not depend on whether the family lives in the rural or urban area or on the socio-economic level of the family. This situation, which can be examined through the "normal" representations of woman and the child mentioned in the first sections, requires a more detailed analysis. However the fact that how quickly the narrative of the *angel mother* turns out to be a *guilty mother* is striking and needs to be considered.

As previously mentioned in Palmira Brumett's text, woman can easily be represented in a position that enables a national imagination to be the desired bearer or accused, satirized and miserable. This can be legitimized based on the emphasis on the nature of woman and on the "normal woman". Or it may be politicized through social values. For this thesis, it is one of the main reasons why I examine the ‘normal’ of society through values and representations. I think that the debate which assumes that the non-visible functions well is problematic. Gender is not a notion which we can explain here uncomplicatedly. However, I must insist that the ideas about discrimination are related and come out in different areas of life through different situations.

Gülser Hanım says,

> In our society, you can leave a healthy child alone with your neighbours, or with your relatives for a few hours. However, they do not want to look after your disabled child for two or three hours. They do not want to take responsibility because they do not know what to do. Society and close relatives do not blame themselves in such a case, but they feel a little bit ashamed, they try not to make you feel it, but strangers may be rude. Now, my child, my daughter with Down Syndrome, has a certain character.. The society looks at her as if she is living in the cage. I used to take my daughter with me while I was going to work. When we go down to the ferry in Eminönü, or we go to the bus station, my daughter asks me, why are these people looking at me like that? Once I told her that, they are thinking that they saw this beautiful girl on TV. That’s why, they are curious about you.

Fadime Hanım says,

> Most people do not accept, they do not care who you are. Okay, there are people who have affinity with Kaan, but there are no kind thoughts for me. For example, anybody does not think that this woman or this girl is running all day long, she can eat at our home today, or we can help her ... There is no one who understands us. We're bad if we do not do anything to one. I'm telling you seriously, even in this situation, this is what happened to us. My relatives and my family got angry, saying that you take Kaan everywhere, why don't you come to us.

Yersu Hanım said, "those who gave huge reactions in my family were those who inclined away from us, but friends around usually supported us".

İstemihan Hanım says,

> Everyone approached us with a deep mercy, tried to show a lot of compassion. Actually, they tried to do a favor for us, but more of than that, they reminded us our disability. Some things that we were not aware of, they showed under the name of mercy. I always felt a mercy, compassion or blindness. That was always negative.

"Not knowing what to do" and "moving away" were other common reactions of the people towards the families with disabled children. Many of the families told that their surroundings became narrower and their borders were widened with their friends. We can interpret this situation in terms of two different aspects, of which one is the identification of disability and the other is the importance of the child for presence of family within the community. As previously mentioned, the idea that disability is not constructed by society and "disability is the impairment itself" is a comfortable way to ignore how individual people play their role in the construction of disability. This argument, which will be discussed in more detail in the next sections, and its supporting narratives can explain why a family with a disabled child is exposed to this kind of marginalization.

İbrahim Bey says,

> I did not share it with many people. We have not shared much with grandmother, it was something that they can see while Efe was growing. We

> did not even know what to do... because yes we knew he is disabled but the disability has very different aspects. As we faced this problem since his birth, we saw what he could and could not do slowly in two years as he grew up. This is not something that doctors can predict in advance. They also watch and wait to see what he can and can not do. So, we cannot estimate anything about the future.

4.1.3. The Growth Process

In this section, I try to put the answers together, which are given related to the growth of disabled child. One of my questions often lead to a deeper conversation. I asked to participants, "Did your feelings change in your child's growth process, if so, how?". When I started to talk about the *changing of feelings,* the conversation often went to different subjects that I could not imagine.

First topic is the education. Education does not only include public education system but also private space and parent-child relationship. I have chosen this title of the section because the parents mentioned about their children's growth in a way that concerns the education they receive, even though there was no question directly related to their education. Also, one of the places where the families most often encounter with society's approach to disability is the area of public education. If you have a disabled child who has got an education in the inclusive class, you can clearly observe the behaviour of other families.

Another important issue about education is that how the concerns and anxieties of parents about their children's future shape this educational process. According to the narratives, the concerns of families about whether the society will accept their children in the future or how they will find themselves in society reveal their fears, rather than concerning about their children's own capabilities.

In the second section, I focus on how families feel about the ableism in society, the situations they find themselves in the public spaces and the attitudes of strangers. However, here, this thesis refers to the inactivity of the rigidities that "normal" reveals, but it is also written with the intention to produce alternative possibilities. There was not only pain and sorrow in the stories the families. Besides, the stories display a wide range of experiences on how to establish a collectivism and how to set up a relationship by including the differences during the growth process of children.

4.1.3.1. Education at Private and Public Spaces

After *accepting* their children's disability, Suna *Hanım* started to search for her children's education possibilities. She told that education opportunities for blind children were quite few in the years of 2000. Besides, it is also very difficult to reach the places of education or to the people who provide the education. She implied that especially first years are quite important for children's education and most of the parents do not know how they should act. She said how they behave to the children with visual impairment when they are still kids may cause autism in the children:

> We somehow started education, which has first taught me what I should do and what it was exactly the opposite of what I did. For example, we are putting the child on the bed, our children are standing well, shaking, sleeping, waking up, eating, drinking, throwing in, and so on. They give us papers, we read them. You will not leave the child. You will tell them what you're doing. The child will always be with you. What I did was developing autism in the visually disabled child, in fact we saved one of our children from developing autism. We, then, started to take the children to the saloon and the kitchen, everywhere with us. Mrs. Hale always said that, do not think that they do not understand the conversations. They absolutely understand. Indeed that was true. They began to talk very early.

It is necessary to decide which school to go before the children reach to the age of primary school. Suna Hanım was influenced by what she saw in the school of the blind children and then, she has decided to prepare the children for "inclusive education".

> That day, I went to the school for blind children. The school for blind children deeply affected me. A lot of kids do not see. They hold each other and walk together. The situation was snafued. Many children were there and I felt myself really bad. I said to Mrs. Hale that I wass feeling myself bad. She explained that there is an inclusive education system where children go to the same state school together with their coevals... With private lessons, etc., we are preparing our children for inclusive education system. Schools did not tend to accept our children, it was a struggle. After one year of pre-school education, our teacher said, Mrs. Suna your children's finger muscles

> are very weak. You know, Braille, something like a spikes, it requires strenght. We decided to send the children to the school for another year, but the manager did not accept. I got stuck again. There was a teacher, she loved our kids very much. Children hold her dear in the first grade. This time she was a reluctant. W asked "Why do not you want?" I cannot make it, she said. Until she was first grade, our children had already learned alphabet and writing... One day, Fatih came and told that, "Mom, this is not my place, it is the School of the Blind. I don’t want to go to the School for Blind". Later, we -20 people- prepared our children for the inclusive education.

Gülser *Hanım* was a teacher when her child was born with down syndrome. She said that this situation may have given her maneuverability for her child's education:

> In the beginning of the process, you do not know what to do and how to do. Then, of course, you accept the situation. I thought that I am an instructor and what can I do? Then, I said to myself, I have to do my best and I searched a way to realize this goal. I turned this around quickly because it gave me hope her reactings to the slightest warning, I have been trying to improve it. Perhaps that was an effect of my profession. I forgot about disability when I started to search about improving my child’s talents. Even if it is small, every success is motivating you. If you ask me what I learned, my answer would be that little things can make you happy, because regular families who have healty child want a profession for their children that the children cannot engage,. I do not apply pressure to my children because I just want then to gain basic abilities. I did not make my child unhappy. Of course, I would like that she becomes a doctor or engineer but then, in this case, she cannot be always with me.

Gülser Hanım told me a memory from when she was a teacher at a school in İçerenköy. She was teaching in a special class, and one day, the school principal called her. The principal asked whether the students in her class and the other students in the school can make a break at different times. When Gülser Hanım asked the reason of this request, the principal said that eight students with intellectual disability in special class scare the other students. Gülser Hanım says that she answered this request, “You have 500 children, and they were afraid of these eight disabled children, I cannot understand, maybe the others would have harmed them. I said no because these children live in the same neighborhood. When they leave the school, they play on the streets, I said how can you imagine such a thing".

She also said that the families of other children in the inclusive class do not want the disabled children in the classroom. They were collectively trying to restrain the disabled children from getting education in the same class with normal children.

Indeed, I often heard this information from teachers and parents whom I talked to about the inclusive classes.

Nilay *Hanım* has two children. The older one is called Deniz, who has cerebral palsy and she defines the growing process:

> Of course I see a lot of things around, the parents treat their disabled children as if they are babies, they do not behave according to their age. They're doing everything for their children. They are doing whatever they can do for them. If I am acting a little differently, I might be treating my son more disciplined because I want him to be someone who is better-natured and has better relationships in society, because it may be something like my daughter, a hussy woman in her adult life, or even a person who people do not like. I mean, I hope she does not, but despite everything she can look after herself. However, in adulthood, he will need an assistant for the things he cannot physically perform. In addition, it seems to be more important that his personality is smoother. It seems to me that it is more important for people to have better relationships with him so that he can live independently. So, I treat him with much less tolerance. I can be in panic when I see his selfishness and mistakes. I think this idea exists withinall the families that what will happen to my child when I am not there for her/him anymore. S/he should be as independent as possible, even if not physically but in his relationships. Free and happy relationships need to be established.

İbrahim *Bey*, the only father who participated in the research said:

> There is no big difference among the parents who have disabled and non-disabled children. Whether disabled or not, the child needs a mother and father and the parents meet the needs of the child. It does not matter what is the need, when the situation gets locked in here. In fact, the needs of all children who are similar to each other are much greater than the needs of disabled children. 80 percent of all children have similar needs. In fact, 5 percent to 10 percent have a difference. However, he also eats, he gets dressed, and he has to go to the school and come back to home.

Sinem *Hanım* who is the mother of the triple daughters with cerebral palsy said that we were seriously worried about their future in the beginning. She expressed that they focused on everyday life and set small targets and this method managed to keep them happy.

> I used to see bigger children in the treatment center, and when I saw them, my anxieties suddenly became apparent. I thought I will carry Esra always on my laps, I've been worried about such a future, but later I realized that everything we do make us happier when we start to go through our daily life activities and not thinking about the future, and I see that my worries were a waste of time. I started to live the life day by day, and I was getting happier as we achieve our goals with my children.

When I asked to Sinem *Hanım*, how is the relationship among the siblings and how does it affect their daily life? She answered:

> In other words, my children were able to catch their peers, especially since they are very open to cognitive activities. So, they went to the same schools with their peers. There are many aspects that Esra and Tuğba helped Büşra for because she was heavier, and more dependent on me than her sisters. It is very positive to see the same cooperation that happens around the circle of healthy siblings also between disabled siblings.

When she was talking about the process, İstemihan Hanım said, she had no hope at first that her son would walk and talk, her thoughts changed towards a positive direction day by day. She also added that dealing with a disabled child is very expensive and people's behaviours often change according to the money you have in your pocket.

4.1.3.2. Reactions of the Society and Being in Public Spaces

In this section, families which have a disabled child are presented with their feelings and thoughts about being in the public space. Concurrently, the impressions of the families about "ableism" and the family's thoughts of the other families which have a disabled child are also indicated. It should be noted that the discussions about the growth process of the children do not provide a holistic approach towards the subject of disability and it is intrinsically dark. This section contains the families' feelings about exclusion and their anxiety about their children’s future, as well as the possibilities they have experienced. It can be asserted that the solidarity, re-framing the situation and considering children's own feasibilities can be utilizeda as a "strategy" for facing the ableism of the society.

Suna *Hanım* says that even though only the eyes of her children do not see, still, when she is with them, they always ask questions related to their names or what they should eat. Combination of intellectual and physical disabilities is not only unique to people with cerebral palsy. It is important to recognize the approach of society to disability with the idea that disability is socially produced, even if medicine insists on distinguishing between these two types of disabilities or it is discussed to be so in theory.

> When I eat with my son, people ask me what my son is going to eat. Actually, they have to ask my son. I never answer on behalf of my son. They are asking me the name of my son. I always tell them to ask him directly. There are things that not only us but others need to learn. Hale Hanım said that many questions are asked about them, many people will come to them. There are a different kinds of people in society. Never respond them inversely when they ask questions specific to your disabled child, they might be meeting a disabled child for the first time in their life. Do not answer in reverse sentences. However, we are tired... We don’t want to stay at home, we want to socialize. One day, we went to Yıldız Park. One seller had understood that the children do not see. Now, it cannot be recognized from distance, the young kid, you hold his hand in a natural way, but after a while they understand. He asked that is he blind? I said, yes. He said did you bring him to the doctor? I said “No, I am content with this situation”. Once, I was looking for a newspaper, the children would be on a newspaper because they had participated in an activity. I checked the newspapers because I did not know which newspaper I should buy. The man asked me why my children are on the newspaper? My children do not see, they participated in an activity like this, I replied. Who knows what kind of crime your committed, he said. I went out. Other people who ask about disability seemed to me very innocent after then. My sons always ask, why do people ask? I say it is not a problem, they can ask. I also wonder what causes it when I see someone with a disability. When somebody asks us we can talk about it, and you can talk about. We never keep that they do not see, people recognize and ask, yes, they do not see, we respond naturally. I mean, not to charge the kid with guilt, he is not guilty. I'm not guilty either. Everyone has a nature. Some children have heart disease, it is invisible from the outside, but

> they have to live a much more passive life than my children. People may have different kinds of disabilities. As I said, we encounter a lot of things in society. It is not only me, all mothers with disabled children.

Suna Hanım now says that her children continue to high school and that the process is mature for them. “Since we live with the situation, we come together with visually disabled people who are in good situation, so there is nothing that they are forbidden to do. If they say they want to do something, I do not say them that they cannot do it.” However, she added: “This is the thing that I fear the most. When you enter a place... We do not look like that, but in the first place, I think that they can suspect we are beggar. It is thought that blind people are always beggars. That’s why, I feared to be accused of robbery. They do not do it anymore, but when they were younger they were touching everything they see. This is how they can perceive things, they know no other way. He does not know that the bag belongs to someone else, they look into it. Apart from that, I have no problem with life”.

İbrahim *Bey* talked about increasingly narrowing circles of family surroundings,

> Our connections were more and more disappeared. There was a lot of friends and family who were far away because of their cowardice or because they did not know how to act. People may display strange behaviours because they do not know what to talk about, or because they cannot feel like they are ready for it. However, this brings a different situation, in which single couples travel with single couples, families with young children are better friends with those who have young children. Therefore, families with disabled children, increasingly tend to form groups to share information among themselves both as a group of solidarity and a natural development.

İbrahim Bey stated that the common feelings of families for disabled children lead to a form of solidarity among each other. He says that people who do not experience having a disabled child think that they cannot understand this situation, and so this naturally brings the families with disabled children closer. Sara Ahmed's aforementioned statement that people tend to identify "pain as a individual experience which is not possible to be shared with an outsider" may show us the lack of communication. According to Ahmed, there is no single way of looking at someone else's suffering, and everyone produces methods to accept the pain that occurs in front of them. (Ahmed, 2004) This can be considered as an another way of sharing a different kind of solidarity.

Yersu Hanım emphasized that their lives started to take shape according to their children's comfort, “We were a little restricted, we could not go to everywhere we wanted, we could go to the place where we could be relaxed and comfortable with him. In some aspects, we have restricted ourselves”.

Nilay *Hanım*, says that it is essential to go out for the transformation of the dependent relationship between the child and the family.

> Families with low socioeconomic status may be less likely to go out. Hence, more individual, intimate and dependent relationships can be developed. I've tried to avoid this very much, yes, he is physically dependent on me but I did not want our relationship to be sticky. I wanted to have different social lives in the same way that he can meet as many people as possible out there. I've tried hard for this, and it's been a while. However, if the financial opportunities would not be very convenient to go out, we may not have succeeded. Though the activities we choose may not be the activities we spend a lot of money on, nevertheless, that is a huge plus for us. Deniz is 17 years old and he is on wheelchair and we have our own minibus and there is a ramp behind. I can take him everywhere with our own car. I could not do this if I did not have the minibus, this cannot be done with public transportation unfortunately, because they are not suitable for the disabled. ... Of course, this condition have also contributed to the establishment of a healthy relationship, perhaps a mother who is constantly at home with her disabled child is both loving and secretly become furious, a mother. I do not know, there is absolutely.

Gülser *Hanım*, is one the founder of “The Tomurcuk Cooperative”[36] and she expressed that it is very important to be visible to be recognised.

> Families with a disabled child feel frustration because their children do not understand what it means to stop. They do not go to public spaces, both they and their children. Maybe if they get rid of this idea, society will recognize them. Other people need to get used to this situation. The child will gradually adapt to the regular life in the society. The family actually feels guilty, so when they go out they can’t get along with the society’s way of living. The families need to be organized in this regard. We have to fight together. When we found this place, we say that we will not separate our children from the rest of society. We were going to a bakery in Bağdat Caddesi, but collectively with 30 people to celebrate a birthday. People were

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[36] Tomurcuk Kooperatifi

> staring at us directly. Really. We were sitting in the front. An old man asked to the waitres why he gave us the seats in the forefront. When I realized, I asked to the waitress what the man said. Then, I asked how he answered: if you're disturbed, you can go, sir, he said. He is a worker. At that point, families trusted in but they were still anxious, although all the mothers had a bachelor degree. Since she/he is an individual, an individual who is disabled. She/he has all the legal rights you have, However, he doesn't know her/his legal rights. For mental disabilities, I express this for mental disabilities, then you need to defend his/her rights on behalf of your child. You need to know what those rights give you as a parent of disabled child. The educated group knows more, but the other part of the society doesn't know. Unfortunately, there is no right in our society unless we demand it. So, society needs to be conscious in this sense, and the disabled people also need to be visible. Whatever you want, you have to demand it.

When we talked to Fadime Hanım about her perceptions and feelings about the raising process, the issue came to her wishes when she decided to have a child. She said that her willingness about having a healthy child and having Kaan are completely different things and they cannot be compared.

> I am accustomed to live in this way, I am acting according to how I should be doing. I took care not to have any other perspective. Even one day, when Kaan was four years old, we were waiting for a bus. I did not look at it with malicious intent. One woman was holding the hand of the child and I stared at her from her back. Kaan said, why are you looking at them? He said you're looking her because I cannot walk. I was incredibly impressed. How Kaan got to mind. Of course, I would, but we always believe that we will come to better places to walk. Even when Kaan was two years old, the doctor said, "What do you expect from him?" He tried to say that nothing would happen. The doctor told me that when Kaan was a baby, you would take him home and you should not move him at all. Zero movement, he said. I did not even listen to the doctor. I know doctors are more conscious, but let go of things on its own. If I had listened to the doctor, Kaan would not even be able to go to school from home.

4.2. EVALUATION OF THE FINDINGS

The field research proceeded in a semi-structured form and through open-ended questions, it was not designed for collecting information. The main purpose was to record the experiences of families about the disability of their children. At the beginning of the interviews, questions about work, age, marital status, education levels were not asked. The parents provided this information if they wanted to do so. The most pre-determined theme in this research is about the "space" between current feelings of the family and when they learned that their children are disabled. Similarly, there are other researches about the feelings of parents when they learned their children are disabled. In this research, the first feelings observed were fear, anxiety, shock, sadness, disappointment, desperation. “Our world was destroyed.”, “I could not see the future.”, “We had no idea what we have to do.” was some of the answers for defining these feelings.

One of the main assertion of parents was the inadequacy of medical advice on possible experiences and the lack of guidance. Parents had to find themselves how they should behave to their children and what kind of education their children need through their own opportunities and connections. Besides, they expressed what they have learned in the following years as that their behaviours towards their children in the very first years may cause them to develop other disabilities. It is possible to say that these findings of the field research are crucial. As indicated in the beginning of this study, one of the motivational sources of this thesis was what happened to the child during and after the family has learned about the child's disability and accepted this situation. It would be more appropriate to postpone this debate as a matter of further research, since it is necessary to get help from psychology's methods which describe the relationship between the family and child for such an endeavor. However, it is still worth to place an emphasis on education here.

It was realized that the parents' approach to education was generally based on bringing their children to a "more advantageous" position than the others. The parents think that the way to ensure that their children exist among healthy children is to support their children as "qualified", "equipped", "nice temperamental" and to take the necessary steps for it. It is not difficult to understand why, but it is necessary to realize that it is a desire to exist within a “normal” community. When I talked to Umut Koşan who has cerabral palsy and gives consultancy to the families who have disabled child, he told me that everybody cannot have the same opportunities in life and to force a disabled child for a certain success that may cause a kind of discrimination. The above-mentioned biopolitics is also decisive in determining the educational priorities of the families who have a disabled child, and want their child to become more productive and to put them in a capitalist circulation.

Another remarkable result about education was related to "inclusive classes".[37] Many of the interviewees whose children attend to the inclusive classes said that other parents and even the teachers were uncomfortable because of a disabled child in the class and, if necessary, gathered to oppose it. Parents said that their children were making great preparations before the inclusive classes and this secluded attitude was also extremely influential on their children. There is a belief that this situation happens more in public schools, although we cannot say for certain.

Even though the behaviours and reactions were mentioned in various ways in the families' close surroundings and relatives, the families' feelings were defined through the attitudes of society toward their children as "cruel" or "unable to understand their experiences". Studies that investigate the functioning of families in Turkey indicate that the families in Turkey both in rural and in urban areas are nuclear family-based and “functionally extended” (Berik 1995, Delaney, 1991; Starr 1989; Timur 1972), but most of the participants think that the support they receive from first-degree relatives is inadequate. As a remarkable result, Suna *Hanım* who has twin children, and Sinem *Hanım* who has triple girls, stated that

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[37] For more detailed information about “inclusive classes”: Çayır, Kenan ve Ayan- Ceyhan, Müge..(der) (2012) Ayrımcılık: Çok Boyutlu Yaklaşımlar, Sosyoloji 15 - Eğitim Çalışmaları 2, İstanbul: İstanbul Bilgi Üniversitesi Yayınları., s: 18.

they received a lot of support from their families. Besides, during this study, it was noticed that the most significant support groups for families with disabled children are other families who also have disabled child and, non-governmental organizations.

With regard to the acceptance process of the families, "destiny" was found in related discourses. "She/he also *can*", "Everyone has a creation." Such statements appeared especially when the families talked about their situations for the first time. However, as the relationship progressed, it became evident that these discourses had evolved into a position seeking opportunities and rights. Concepts such as "charity" and "destiny" produced by religion about disability are considered to be quite important in order to understand the ableism in society, but they are so comprehensive and they can be the topic for a thesis per se.

The dynamics of gender have been explored through the question that whom the children are most associated with at home. The answers given to this question were more likely to be that the dad works and as a "natural" result the mother is more associated with the child. The second response about men's out-of-raising period was that it might be related to the distribution of gender roles in society and forms of "upbringing" in their childhood. The fathers were imagined with the features like "loving" but "do not enough patience" or "going", even "embarrassed from their disabled child".

İbrahim *Bey*, the only father among the interviewees, noted that the needs of the disabled child are much more than the other children and that everyone should be involved in the growing process. He said, “Sometimes they tell me something, Efe is lucky because he has two mothers. As a result, there is now a loosening of the role of the father, and the needs of the disabled child are more than others”. This can be considered as one of the most striking results of this research because how the parents define their gender roles is also convenient to discuss the unpresented possibilities within the family with disabled child.

The strategies developed for the physical absence of the father had two forms: rying to break the dependency by strengthening the other relationships or, intensifying the mother role. İstemihan *Hanım* who has a child with CP said: “If

Samet would be healthy, our communication would not be that strong, because he would be very independent. Now, he needs my body and I need his love and our relationship is more intimate.” Nilay Hanım says that even if her child is physically dependent on her, she tries to make him as independent as possible by supporting the development of Deniz' social relations. It should be pointed out here that giving an explanation on two examples is insufficient and a more comprehensive and bi-directional research is required on the role of motherhood.

Another of the interpretation of findings is the importance of external stimulus. Almost all the families expressed that being present in the public and the interactions supported both themselves and their children. The existence in the public space itself has occasionally emerged as a resistance strategy for the families. It is stated that being visible does not only make it easier for the children to be educated, but it is also an essential part of the work which is necessary to get their rights.

The last point that is mentioned in this part is the clarity between the emotions of the families about the first times that they learned their child is disabled and the emotions about the growthprocess of their child. As mentioned earlier, the parents respond positively to the question "whether there is a difference between what they feel when their children was born and their current emotions". This study assumes that Çiğdem Kağıtçıbaşı's Value of Children research emerges as a functional view of the social value of the child. It is related to "healthy" and "normal" child and is suitable for exploring the ableist view of society. The first feelings of the parents receive a share from this ableist perspective and their feelings/emotions/thoughts have being shaped by the potential of the possible thoughts that they got as they first "meet" their children. The experiences of the parents are avowedly and widely presented here. Accordingly, I attempted to investigate the possibility to provide an alternative view to the existing "healthy"-"disabled" child dichotomy.

CHAPTER 5

CONCLUSION

This thesis endeavor to explicate how the families with disabled children experience the disability in an ableist society and within the existing power relations. Disability studies research on Turkey so far does not include the experiences of families with disabled children. It is expected that this fieldwork will contribute to the literature by producing information about the disability experiences of the families with disabled children.

Eight people participated in the field research, their support made the research process much easier. The fact that İbrahim *Bey* was the only father among the interviewers can be considered both one of the findings of the research that is related to gender and as a restrictive factor of the research.

The findings are collected in three main areas. These areas are comprised of what the families felt when they learned that their children are disabled, what they experienced when they shared this knowledge with their surroundings, and what they felt/experienced during their children's growth process. According to the experiences of the families, first of all, their anxieties were about the abilities of their children. In the growth process of their children, their concerns were transformed to how their children can exist in the society they live in. It seems essential to look at these concerns/experiences in order to examine ableist relationships in society and to resist to discrimination.

The experiences of the families themselves were a criticism of the medical approach to disability. They clearly stated that doctors' diagnosis were insufficient to explain possible experiences, and that not all experiences under a certain medical diagnosis are similar. The families noticed that they had to identify their childrens' needs themselves and they were trying to reach the required education on their own. The family's thoughts on the growth process of their children were oriented more towards the educational processes. Accordingly, important data about “inclusive classes” have emerged. The families said that their children are not wanted in these classes. Another piece of information about education was that the disabled children should be better equipped than "other" children. Another important finding was that the person most associated with the child in the family was usually the mother. Looking at how disability policies are structured in Turkey gives important data on the responsible person caring for the disabled child and his/her education. One of the most important reasons of this is that the social policies in Turkey put the responsibility of caring for the disabled person on the family and do not provide professional support.

Throughout the research, theoretical focus was first of all on how the normal is established on the representation "stage" and how disability studies address this structure. Additionally, I tried to analyze how the normalcy of family is built by reference to the “function” of the family and cultural values of society. During the study period, I realized that delineating this relation requires to bear many separated dynamics about family and society in mind, which was a true challenge for me. I insist, however, that any concept or situation is not composed of itself, and that it is more meaningful to examine it through its bonds and relations.

Before the research process started, one of the questions in my mind was the relationship between disabled child and the family. Regrettably, as I was investigating the literature for this research, I realized that the explanations about the disabled child were always made over the issue of "impact", which meant the "bad impact" that the child had on others. I did understand that such a research is an eloquent one, but it requires both a broader, bilateral field research and receiving help from theoretical grounding of psychology and social work departments.

Disability theories have been studied in detail since it is desirable to look at where they sit within the mind/body duality produced by the modernity, which determines society's view, and how the theories are established on the basis of relationship between the “normal” of society and disability. It is the basic hypothesis of this thesis that a family with a disabled child can have a share in the conception of a child who is considered normal and healthy, and at the same time is influenced by the social norms and interventions produced through these values and power relationships. By this way, the family experiences can be recognized as a field of research.

It is a crucial finding that the families' view on disability are changing in the growth process of their children and, their concerns of the future are turning to be about how their disabled children can exist in the society rather than concerning about their children per se. The most fundamental point which this finding implies is the possibility of *staying together*. This possibility, which emerges with recognition and relationality, is itself what the researcher wants to reveal.

APPENDIX: FIELD RESEARCH QUESTIONS

Aşağıdaki sorular, Türkiye toplumundaki sakat çocuğu olan ailelerin sakatlığı nasıl deneyimlendiğini araştıran bir tez çalışmasında kullanılmak üzere kurgulanmıştır. Sorular hazırlanırken evet-hayır soruları yerine açık uçlu sorularla ilerlenmesine ve soruların herhangi bir yönlendirme içermemesine dikkat edilmiştir. Görüşmenin yarı yapılandırılmış formda gerçekleşmesi planlandığından, görüşme anında akış ve sorular değişebilir ama bahsedilen iki husus göz önünde bulundurulacaktır.

- Çocuk yapmayı isteme sebebiniz neydi?

- Çocuğunuzun engelli olacağını/ olduğunu öğrendiğinizde ne hissettiniz?

- Çocuğunuzun büyüme sürecinde hisleriniz değişiklik gösterdi mi, evetse nasıl?

- Çocuğunuzun engelli olduğunu çevrenizdekilerle paylaştığınızda bu durum nasıl karşılandı?

- Çocuğunuzu büyüttüğünüz süreçte çevreyle etkileşiminiz nasıldı?

- Engelli olmayan başka bir çocuğunuz bulunuyor mu, bulunuyorsa kardeşiyle ilişkisini nasıl betimlersiniz?

- Çocuğunuz evdeki bireylerin hangisiyle daha yoğun bir ilişki geliştirmiş durumda?
- Sizce ekonomik durumunuzun çocuğunuzla kurduğunuz ilişkiye bir etkisi var mı, varsa nasıl?

- Size benzer deneyimler yaşayan aileler ya da engellilerle iletişime geçtiniz mi, evetse bu dayanışma size ve çocuğunuza nasıl yansıdı?

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