RETHINKING DISABILITY AND MOTHERHOOD: THE EXPERIENCES OF
MOTHERS' OF DEAF CHILDREN

by İzem Aral

KOÇ UNIVERSITY
2018

SAKATLIK VE ANNELİĞİ YENİDEN DÜŞÜNMEK: SAĞIR ÇOCUKLARI OLAN
ANNELERİN DENEYİMLERİ

A Thesis Submitted to the

Graduate School of Social Sciences

in Partial Fulfillment of the Requirements for

The Degree of

Master of Arts

in

Comparative Studies in History and Society
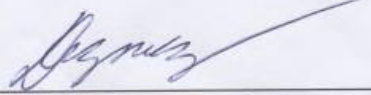
Koç University

August 2018

Koc University

Graduate School of Social Sciences and Humanities

This is to certify that I have examined this copy of a master's thesis by
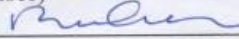
İzem Aral

and have found that it is complete and satisfactory in all respects,
and that any and all revisions required by the final
examining committee have been made.
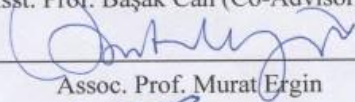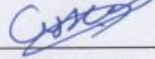
Committee Members:

_____

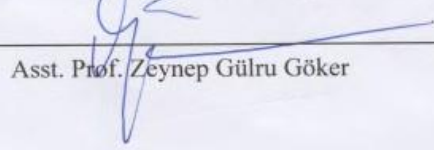Asst. Prof. Dikmen Bezmez (Co-
Advisor)

_____

Asst. Prof. Başak Can (Co-Advisor)

_____

Assoc. Prof. Murat Ergin

_____

Asst. Prof. Ayşecan Terzioğlu

_____

Asst. Prof. Zeynep Gülru Göker

Date: 29.08.2018

RETHINKING DISABILITY AND MOTHERHOOD: THE EXPERIENCES OF MOTHERS' OF DEAF CHILDREN

İzem Aral

The welfare and healthcare structures and hegemonic social and cultural discourses in Turkey inform mothers' understandings of deafness. First, by laying out mothers' experiences of medical procedures including diagnoses, hearing tests, hearing aids and cochlear implantation in settings such as hospitals, rehabilitation services, and schools, this thesis examines how mothers make sense of disability in their encounters with medical and rehabilitative experts, school teachers, doctors and family members. Second, this thesis also examines how mothering experience is transformed in relation to caring experience. I investigate mothers' experiences at two levels: I examine the mechanisms through which mothers are reproduced as the main caregiver for disabled children and how mothers, doctors, medical and rehabilitative experts, teachers and family members reproduce the idea that women are the primary caregivers for the disabled. Second, I tease out how inadequate healthcare services and unequal division of care labor in the family push these women to engage in public advocacy concerning the rights of their disabled children. Drawing on the mothers' advocacy work in the "Association for Families" (AF), which was founded by mothers in 2004, I analyze how mothers translate their own difficulties in medical and educational settings into a struggle for improved services.

Keywords: Disability, Motherhood, Deafness, Care, Sign Language, Cochlear Implant, Family Advocacy

SAKATLIK VE ANNELİĞİ YENİDEN DÜŞÜNMEK: SAĞIR ÇOCUKLARI OLAN ANNELERİN DENEYİMLERİ

İzem Aral

Sosyal devlet ve sağlık hizmetlerine ilişkin yapılar, hakim kültürel ve toplumsal söylemler annelerin sağırlık mefhumu üzerindeki düşüncelerini şekillendirmekte. Bu tezin öncelikli amacı, annelerin, hastane, rehabilitasyon merkezi ve okul bağlamındaki tanı, işitme testleri, işitme cihazları ve koklear implant gibi medical süreçlere ilişkin deneyimlerini açıklayarak; annelerin rehabilitasyon uzmanları, öğretmenler, doktorlar ve diğer aile bireyleri ile bu süreçteki karşılaşmaları sonucu sakatlığa ilişkin nasıl bir anlam dünyası edindiklerini anlamaktır. İkinci olarak, bu tez annelik deneyiminin bakım emeği etrafında nasıl yeniden şekillendiğini izah etmeyi amaçlamaktadır. Annelerin deneyimlerini bu bakımdan iki şekilde ele alıyorum: İlk olarak anneliği çocukların bakımından sorumlu temel aktör olarak yeniden üreten mekanizmaları ele alıyorum. Ve yine, annelerin, doktorların, tıp ve rehabilitasyon uzmanlarının, öğretmenlerin ve diğer aile üyelerinin anneliği yeniden üretmedeki rollerini inceliyorum. İkinci olarak da, annelerin yetersiz sağlık hizmetleri ve eşitsiz olarak pay edilen aile içi bakım emeği karşısında çocuklarının yararlanabilecekleri hakları iyileştirmek adına hak savunuculuğuna ne şekilde eklemlendiklerini açıklıyorum. Bu anlamda, annelerin aileler için 2004 yılında kurduğu bir dernekten yola çıkarak, annelerin tıbbi ve eğitim süreçlerinde karşılaştıkları zorluklardan hak ve hizmetler için yaptıkları savunuculuğa uzanan yolu inceliyorum.

Anahtar Kelimeler: Sakatlık, Annelik, Sağırlık, Bakım, İşaret Dili, Koklear Implant, Aile temelli savunuculuk

ACKNOWLEDGMENT

LIST OF ABBREVIATIONS

CI: Cochlear Implant

AF: Association for Families

ADP: Association for Deaf People

BERA: Brainstem evoked Response Audiometry

İstanbul Provincial Directorate of National Education (*İstanbul İl Milli Eğitim Müdürlüğü*)

MNE: Ministry of National Education (*Milli Eğitim Bakanlığı*)

SERC: Special Education and Rehabilitation Centers (*Özel Eğitim ve Rehabilitasyon Merkezleri*)

SSI: Social Security Institution *(Sosyal Güvenlik Kurumu)*

TSL: Turkish Sign Language

3E: Early Diagnosis, Early Education, Early Implantation (*Erken tanı, Erken eğitim, Erken cihazlanma)*

Chapter 1

1. Introduction

This thesis inquires into the experiences of families–specifically mothers–of deaf children in İstanbul. This research particularly focuses on mothers' experiences because maternal labor is seen as responsible for the bulk of the care work for children in Turkey. Therefore, although family is also an important concept for this thesis, mothers are the "smallest unit of analysis" (Traustadottir, 1991, p.212) to understand how caring for a disabled child is articulated within gendered social family roles. By laying out mothers' experiences of medical procedures such as diagnoses, hearing tests, hearing aids and cochlear implantation in settings such as hospitals, rehabilitation services, and schools, this research examines how mothers make sense of disability in their encounters with medical and rehabilitative experts, school teachers, doctors and family members.

The welfare and healthcare structures and hegemonic social and cultural discourses in Turkey inform mothers' understandings of deafness. These very same mechanisms also hold mothers who take care of disabled children responsible for the social reproduction of the household. This thesis examines not only the meanings of deafness for mothers but also how mothering experience is transformed in relation to caring experience. I investigate mothers' experiences at two levels: First, I examine the mechanisms through which mothers are reproduced as the main caregiver for disabled children and how mothers, doctors, medical and rehabilitative experts, teachers and family members reproduce the idea that women are the primary caregivers for the disabled. Second, I tease out how inadequate healthcare services and unequal division of care labor in the family push these women to engage in public advocacy concerning the rights of their disabled children. Drawing on the mothers' advocacy

work in the "Association for Families" (AF), which was founded by mothers in 2004, I analyze how mothers translate their own difficulties in medical and educational settings into a struggle for improved services.

What motivated me to write this thesis was the conceptualization of these topics under Deaf Studies[1], a sub-discipline of disability studies, focused on the identity and experiences of deaf individuals (Padden & Humpries 2006; Friedner, 2011). Mostly informed by studies in Western settings, the foundational idea of deaf studies is that deafness is not an impairment; rather, deaf people are a linguistic minority whose primary language is sign language. The emphasis on common culture that derives from the usage of sign language stands in stark opposition to medical procedures and technologies invented to repair hearing impairments–especially the Cochlear Implant (Mauldin, 2012; Blume 2009; Lane, 2006), a technological aid which is surgically placed in the internal ear and transmits sounds to the sensory part of the brain (Mauldin, 2012). In the literature produced primarily in the US and UK, Cochlear Implants are criticized as being marketed as a eugenicist approach to the deaf bodies who are, in fact, not deprived or deficient (Blume, 2009; Sparrow, 2005). Therefore, the proliferation of medical technologies is conceptualized as a fundamental threat against deaf communities. Especially in the case of deaf children, family is seen as the facilitator of these technologies that diminish their children's right to communicate in their own linguistic terms because children often enter medical and rehabilitative units with their families (Lane, 2006; Blume, 2009).

Drawing on the disability studies, Deaf Studies, medical sociology and medical anthropology literatures, I examine the mothers' role in the making of deafness while taking into account the role of social and medical structures in shaping deafness and motherhood in Turkey. Similarly to Deaf Studies, a line of inquiry in disability studies also conceptualizes

---

[1] "D" (uppercase) in Deaf Studies signifies deaf identity and deaf culture.

family as a collaborator with medical expertise that perceive disability as a deficiency to be undone (Oliver 1996, Cocks 2000, Weiss 1997), disregarding disabled individuals' control over their bodies and making them dependent on both familial and professional care (Morris, 1997). While this critical approach to family's role is crucial for demonstrating how medical approach is integral to family's conduct and understanding, it has two flaws. First it underrepresents why and how mothers accept, negotiate or come to terms with medical structures (McKeever&Miller, 2004; Landsman, 2009; Ryan&Runswick Cole, 2008). Second, it has been argued that the focus on critiquing the family often neglects the care work shouldered by family (Kittay, 2011, 1999; Kröger, 2009; Shakespeare, 2006)–work which is divided unequally "within a gendered nuclear family structure" (Ginsburg & Rapp, 2001, p.540). Following these conceptualizations concerning parenting and disability, my work aims to incorporate mothers' understandings of their motherhood and their engagement with medical, economic, moral and social structures, in order to "capture the shifting, flexible and sometimes uncertain ways in which we all negotiate the world" (Ryan & Runswick-Cole, 2008, p.200).

My engagement with the Deaf Studies literature, and the lack of such a body of literature in the context of Turkey, directed me to look at the ways in which deafness is constructed, understood and managed in Turkey. My research developed into an examination of the extent to which medical and social policies and the existing medical technology market determine families' preferences for and understandings of sign language and medical technologies.

The latest disability survey by the Turkish Statistical Institute, "Survey on Problems and Expectations of Disabled People" (TUIK, 2010), displays, though not in detail, the basic demographic and socio-economic status of the deaf citizens in Turkey. It shows that 5,9 % of the national population is deaf or hard of hearing. In terms of educational and employment characteristics, 31,6 % of the deaf population is illiterate and 73,2% of this population is not

working. The survey implies that the exclusion of the deaf people from the workforce creates a vast household dependency in which 56% of the deaf population is cared for by their families, specifically their mothers.

The statistics above shows the widespread marginalization of deaf individuals as well as the issue of dependency as a result of mothers' specific role in the Turkish context. One of the main reasons for this marginalization is the absence of sign language in the national education system for deaf pupils. Sign language-based education was banned in 1957 and replaced by oralist teaching methods[2] that deprived deaf individuals of basic cognitive and analytical skills, therefore excluding them from education and employment (İlkbaşaran, 2015; Miles, 2009; Zeshan, 2002). Although sign language was officially recognized by the Law No. 5378 on Disabled People[3], enacted in 2005, my findings suggest that the overall change in the education is still far away from being adequate (See Chapter 3).

In terms of medical services, cochlear implantation, hearing aids and rehabilitation services are available to deaf children in Turkey. Since 2006, Social Security Institution (*Sosyal Güvenlik Kurumu*, SSI) covers a child's cochlear implant surgery expenses. Implantation has thus become a realistic option for those families who historically would not have been able to afford this expensive surgery. In addition to this, the Law on Disabled People introduced a set of services, such as rehabilitation and special education services, to support the stages following implant surgery or to assist children who have not received implants but who use hearing aids.

---

[2] The ban on the formal language with sign language can be understood as in line with the homogenous language politics of the Republican Era. Archival work on the history of deaf education in Turkey and late Ottoman Empire demonstrates that deaf schools were already established in the late Ottoman period (Ilkbaşaran&Taşçı 2012; Miles, 2009; Z

[3] http://www.mevzuat.gov.tr/MevzuatMetin/1.5.5378.pdf

My fieldwork suggests that irrespective of whether the child has cochlear implant surgery or uses a hearing aid, family remains at the center of a deaf child's life and experiences. In the case of children who rely on sign language, families are the ones to support and take care of their deaf children who face exclusion from education and employment. Family ends up as the main social institution to assist such children. In the case a child who has a hearing device and cochlear implant surgery, the child's hearing and speech performances are strictly related to education and training of abilities (Mauldin, 2012). While rehabilitation services such as speech and hearing therapies and special education lessons support these processes, they mostly guide families to assist their children's hearing and speaking in their everyday lives and help them to adopt rehabilitative skills for enhancing their children's hearing and speaking.

Before introducing the research methodology of this thesis, I want to first explain why I find the concept of motherhood necessary for this research.

1.1.A Brief Overview on Motherhood

As I set out to conceptualize motherhood within the historical particularity of Turkey, I examine particular ideologies that shaped motherhood in 2000s. Motherhood is a charged concept, prone to transformation in accordance with cultural, historical, social and medical ideologies (Glenn, et. al, 1994). Given Turkey's welfare structure, the lack of access to health services and educational rights render the family a unit of care. The introduction of neoliberal policies in 1980s rarefied social rights, and, with Justice and Development's Party's rise to power in 2002, the AKP manifested its neoliberal perspective in welfare policies.[4] During this period, the AKP sought to consolidate familial support with a set of conservative discourses on and practices of reproduction and gender by attributing prominence to family values

---

[4] Yılmaz (2013) argues the reform on public health insurance provides a more accessible healthcare services for the larger segments of society. Yet, the contributory payments still reproduce "income based inequalities" (p.55).

(Acar&Altunok, 2013; Kılıç, 2010; Korkman 2015; Yazıcı, 2012). In her 2015 article, Korkman elaborates on how neoliberalism and neo-conservatism, two almost contradictory agendas, are tied together with an ideal of the family as the main source of reproduction of the youth workforce that contributes to the neoliberal Turkish economy. Often depicted through "sacred mothers, keystones of the family structure and guardians of the moral-cultural order" (Acar & Altunok, 2013, p.18), motherhood is at the center of this new ideal of familialism and is held responsible for raising productive children to propel the nation's future and economy (Acar & Altunok, 2013; Korkman, 2015).

Motherhood is both an institutional and a practical concept. That means that the institutional context in which motherhood is defined relates to both the potential uses and limits of the conduct of mothering. For instance, how can we imagine motherhood at its limits, where the labor of mothering is considered essential, but does not resound within the ideal content of a healthy family? When this conception of motherhood charges women with raising healthful, able-bodied children to advance the economy, what happens when a mother gives birth to a child with an impairment? How do healthcare services filtered through the neoliberal rationale and the "normative cultural scripts" (Ginsburg & Rapp, 2001, p. 536) on mothering and disability engender the ways in which mothers make sense of the impairment and their own mothering roles? These are the questions that I ask in order to understand how mothers, as the main caregivers, reproduce deafness and are reproduced through available social and medical frameworks. In order to give a more comprehensive picture of motherhood, I also examine how mothers' roles as the main caregiver are strengthened by Turkey's laws on disabled people.

1.2.Family's Role in Laws regarding Disabled People

Policies concerning disabled people came onto the radar of the AKP government, which brought the issue of disability in the political arena more visibly in comparison to former

governments in Turkey (Bezmez & Yardımcı, 2010; Yilmaz & Yentürk, 2017). Specifically, there were two important legislative changes on disability in early 2000s as part of a restructuring of welfare (Yılmaz, 2010). First, the Law no.5378 on Disabled People[5] was released in 2005; second, Turkey signed the United Nations Convention on the Rights of Persons with Disabilities[6] in 2007. Nimet Çubukçu, the then Minister Responsible for Women and Family, presented the Law on Disabled People with this following foreword, assuring that this law introduces a human-rights perspective on disability rights in Turkey:

> … the Law on Disabled People is the heart of equal opportunity, human rights and prevention of discrimination. To achieve this, Disability Rights Act proposes solutions for problems concerning accessibility, employment, care, social security and social progress for the disabled people and their integration by the law. Henceforth, up-to-date legal arrangements that will remove the obstacles on disabled people will soon be implemented.[7]

The law appealed to the mainstream through human rights-based discourse that highlights the independence of the disabled citizens and the prevention of discriminatory acts towards them. Yet, the body of literature that examines the content of the disability rights concludes that the narrow criteria for benefiting from these social policies prevents the law from adopting an inclusive approach (Yılmaz, 2010; Yılmaz & Yentürk, 2017). Accordingly, the social policies do not sufficiently curtail the systematic barriers that exclude disabled children from education and the workforce. Although public expenditures have increased with the law, the majority of these expenditures are spent on cash transfers to those below a specified

---

[5] For the full booklet version of the laws and regulations within the Law on Disabled People:
http://www.erisilebiliristanbul.org/BilgiBankasi/Documents/%C3%96Z%C3%9CRL%C3%9CLER%20KANUNU%20VE%20%C4%B0LG%C4%B0L%C4%B0%20MEVZUAT.pdf
[6] English and Turkish versions can be downloaded from here:
https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html
[7] http://www.erisilebiliristanbul.org/BilgiBankasi/Documents/%C3%96Z%C3%9CRL%C3%9CLER%20KANUNU%20VE%20%C4%B0LG%C4%B0L%C4%B0%20MEVZUAT.pdf

income level; therefore these measures aim to alleviate poverty, rather than promote structural changes (Yılmaz & Yentürk, 2017). On the other hand, the introduction of new medically-oriented policies, such as expansive rehabilitation services and cash-for-care homecare allowances, reduced family to a caring unit that is compensates for declining health and social services budgets which rendered family as the dominant source of support and care (Yılmaz, 2010). In the following section, I will clarify how this law reproduced familial care "as the kernel of the social order" (Acar & Altunok, 2013, p.18).

1.2.1 Family Centered Policies in the Law on Disabled People

First of all, an impairment is assessed by a committee of medical experts and only those graded as more than %40 impaired are eligible for benefits (Yılmaz, 2010). In other words, disabled people are assessed medically in order to be eligible to benefit from rights recognized by law.

There are two clauses under the law that posit family as an important care unit: rehabilitation services and homecare allowances. The introduction of rehabilitation services in the Law on Disabled People emphasizes the role of family as follows:

... Rehabilitation services correspond the individual and social needs of the disabled people based upon the participation and equality in social life. In each stage of the rehabilitation from deciding, planning, conducting and finalizing the services, the active and effective participation of the disabled individual and her/his family is fundamental (p.36).[8]

As seen in the regulation, rehabilitation services expect the active participation of the family. While family is a leading actor in institutional care services, family's caretaking role is also strengthened in the household. The home care allowances foster the familial support

---

mechanisms by providing the family with monthly income.[9] This policy, again, does not support the idea that disabled citizens are now regarded as economically/status-wise independent. On the contrary, it fuels the role of family--mostly mothers--as the main caregiver:

> Neoconservative familialism is operationalized through policies that privatize the care of children and the elderly, the sick and the disabled into the family. These policies financially incentivize care work performed at home by (female) family members, and thus invite women into reward them for inhabiting the normative heteropatriarchal space of the family caretaker (Korkman, 2015, p.13).

While the policies intensify the importance of the family to compensate for the limitations of the welfare system, we can also discursively trace the importance given to mothering with the following statement that Minister of Health Ahmet Demircan gave after meeting with mothers of disabled children at a picnic event in Samsun:

> Our prophet says "Heaven lies beneath the feet of the mothers". You are both gifted by motherhood and tested with disability; and you are grateful without being seditious. Some of you take care of disabled children day and night, relentlessly. I wish that God will remunerate your self-sacrifices at the Judgement Day. You deserve the greatest admiration and everyone should kiss your hands.[10]

This statement demonstrates how raising a disabled child is imagined at state level: it naturalizes mothers'care and caring role and assures mothers that they will eventually be rewarded for their unacknowledged hard work, if not during their lifetimes. Although these

---

[9] Benefitting from cash aid is based on following criteria: First, the cash is provided only under the condition that only the one with blood tie can take responsibility. Second, the disabled individual should not meet her/his basic needs. Third, the cash allowance is only provided for residences of disabled people, whose average monthly income is less than two thirds of the monthly net minimum wage based on the number of individuals they are obliged to look after, regardless of existence of social security, and in accordance with the sum of all kinds of income. (The information is provided from: http://www.mevzuatanalizi.com/en/sosyal-guvenlik/o-senay/engellilerin-evde-bakim-ucreti/)

[10] http://www.samsunetikhaber.net/bakan-demircan-engelli-anneler-ile-piknikte-bulustu/

policies and the statement give us hints about how motherhood is imagined, mostly subject to depictions as "sacred" or "stoic", it reveals little about how the everyday experience of mothers, the primary caregivers, as they care for a disabled child. One of the main aims of this thesis is to concentrate on these lived experiences while demonstrating how mothers experience disability in relation to available social and medical frameworks beyond the established motherhood imaginaries. In this regard, this thesis first of all analyzes the ways in which mothering work for mothers of deaf children is reinforced within and through dominant political and social discourses and practices. Second, this thesis examines the impacts of available policies and medical options (See Chapter 3) that reinforce the medicalization of impairment with a set of diagnostic tests, hearing aids, rehabilitation services and cochlear implant surgeries.

As I will discuss later in Chapter 3, this research suggests that the services provided for deaf children are not adequate and take for granted mothers' role as the main party responsible for their children's performance in hearing and speaking. Yet, because the lack of other choices, such as sign language-based education, and the dominance of a medicalized approach to deafness, mothers find themselves committed to medical treatments to undo the deafness, filling service gaps with their economic and social capital by constantly advocating for healthcare services. In short, this research examines the ways in which mothers of deaf children define, negotiate, and practice mothering and deafness in the context of disability in Turkey.

1.3. Research Methodology

Data collection was primarily carried out through semi-structured, in-depth interviews between March 2017 and April 2018. A total of six interviews with Asuman, Derya, Gönül, Leyla, Sedef and Selin lie at the core of this field study. They are mothers of deaf children

who call themselves "the brain team" of the Association for Families[11] (AF), which they established in 2004 to advocate for the medical and educational rights of deaf children and individuals. I reached out to the association with an-email giving a detailed information about the concerns of my study. My first meeting was with Gönül, a retired accountant, who is in charge of the main work of the Association. Other members of the brain team cannot devote their time to AF on a regular basis due to their jobs, household work or their children's busy schedules. I met Gönül in a small basement flat that AF shares with an organization that provides free psychological consultancy to women who have been subjected to domestic violence. The walls of the narrow working space reserved for AF are covered with huge posters prepared for AF's collaboration with a municipality with the goal of collecting and repairing used hearing aids and distributing them to those in need.

My first interview with Gönül lasted over 2 hours. It took me a while to process the medical terminology she used to describe hearing tests, rehabilitation and legal procedures. I also kept in touch with her, asking questions by e-mail or phone to increase my familiarity with the terminology, procedures, and legal documents and reports that I accessed online or via the Association's archive. My relationship with her familiarized people in email groups and in the Association with me and hence allowed me to contact other active members.

My question set consists of two sections: the first group concerns the individual's experiences and the second concerns their advocacy work. Therefore, I met with each interviewee at least twice; the interviews lasted one hour on average. I met each women individually in places such as their homes, cafes and the Association's office. Additionally, I participated in fundraising efforts at the AF, attended disability panels and a school event organized for purchasing a hearing aid with Gönül. Although the "brain team" is small, in 2017 AF had 257 members who do not actively participate in the Association but receive

---

[11] The names of the interlocutors and the associations were replaced with pseudonmys.

information about the cochlear implant surgery, hearing devices or hospitals to go to for hearing tests.

My semi-structured questions were designed to understand how these women reflect on each step of their experiences of raising a disabled child. Therefore, narrative approach was deployed to understand and explore mothers' personal understandings that "make sense of events and constructs narrative accounts in relation to past experiences and future expectations, and importantly in relation to other social actors" (Miller, 2005, p. 10). Interviews with mothers turned into long meetings in which they explained how their lives–not only as mothers, but also as women and wives–changed after having deaf children.

As stated, my fieldwork with the women consists of a limited number. Not having been able to reach beyond the "brain team" is a limitation for this study. Yet, having been able to listen their life stories and their personal experiences with their children's disability, I had a chance to understand how deafness in Turkey is made sense with the social, gendered and economic dynamics. In addition, I also had a chance to observe which economic, social and cultural capitals create the "lay knowledge" that formulates an association and more specifically the women at the core of this association.

I had a chance to explore diverse experiences of women in relation to cochlear implant surgery, sign language, deaf schools and rehabilitation centers. I asked the mothers of non-cochlear implanted children to reflect on their opinions about cochlear implants. I asked the mothers of cochlear implanted children about their thoughts on sign language. While Asuman's daughter, Elif, and Selin's daughter, Defne, use cochlear implants, Oğuz (the child of Derya), Ufuk (Leyla), Eda (Sedef), and Barış (Gönül) do not have implants. The interlocutors' current or former jobs, ranging from sanitation worker/hostess, banker, accountant, manicurist to sales representative, provided me insight into the influence of different class backgrounds. In addition to the mothers interviewed for this study, I also

12

interviewed two cochlear implant users, Melis and Doruk, a rehabilitation expert and a teacher at a deaf school, both from the Family Association. These interviews helped me to understand the cochlear implantation process and the education system in deaf schools. In order to follow the educational and medical realm that deafness is related to, I interviewed Filiz, a rehabilitation specialist, and Meryem, a teacher, via mothers or cochlear implant users. With one of the cochlear implant user interlocutors from the association, I visited the rehabilitation center and participated in one of his therapy sessions following his second cochlear implant surgery.

1.3.1 How I Conducted Different Fieldwork than Initially Planned:

At first, my plan for this thesis was to conduct multi-sited research and explore deaf individuals' perspectives on deafness, sign language and medical technologies. However, I could not conduct fieldwork with deaf individuals because of my lack of sign language proficiency and the translator's busy schedule. Angrosino (2006) reminds us "selecting a site, however, is not the same thing as gaining entrance" (p.14). Before knowing these limitations, I contacted the Association for Deaf People (ADP) via e-mail and expressed my intention to do research with them and asked for permission to visit. After one month, I received a very short response saying that I could visit the association, but should get in touch with the the ADP's official translator, Havva Hanım.

In my first meeting with Havva Hanım, I learned that most deaf people barely understand written language. She explained that she does all the written work for the organization and therefore could not respond to my e-mails on time. Havva Hanım is the only hearing person at the Association. She comes from a deaf family and has four deaf siblings who are also members of the ADP. She takes care of all hearing-related work, answers emails and phones, helps members who have trouble understanding their medical prescriptions, and assists deaf people who have written work to do. Due to her busy schedule, we could only conduct 3

interviews in 8 months. In each meeting, Havva Hanım kept asking interlocutors whether they liked me, as if she wanted to confirm that they felt comfortable meeting with me.

In line with Havva Hanım's concern, I observed throughout these meetings that my communication in oral language while deaf interlocutors communicated in sign language created a sensory and embodied difference between us, which was not easy to overcome. Havva Hanım had to interpret everything I said or asked my interlocutors in order for us to communicate. Because neither my deaf interlocutors nor I could control Hanım's articulations of what we said in sign or oral language, this way of communicating lost some of our meaning, or, at best, transformed it in translation. Without certainty that we fully understood each other, I decided that without learning sign language it was unrealistic to conduct proper, multi-sited research as I intended when I first started my fieldwork.

Yet, deaf members made an invaluable contribution to my thesis in terms of understanding how vital sign language is for them. Their description of sign language and the deaf community is very similar to mothers' description of their children's understandings of sign language and cochlear implants. Even in our short meetings, the interlocutors expressed that their happiness at communicating with sign language instead of requiring a "brain surgery" to hear. Yet, cochlear implants are also a hot debate topic in deaf peoples' daily lives, especially if they marry a deaf person from a hearing family. Hearing in-laws mostly insist that their grandchild have cochlear implant surgery if she/he is born with a hearing impairment. Although interlocutors expressed opposition to the idea of implantation, they accepted the cochlear implant surgery for their children with the condition that they use sign language with their implanted children.

Throughout these meetings, I also had a chance to see how deaf culture is experienced within the Deaf Association in Istanbul. For instance, the Association is a space where deaf people meet with each other, socialize and find their intimate partners. Therefore, ADP serves

14

as a social club rather than only as a place to struggle against the social problems that deaf people experience in the spheres of education or employment.

To sum up, I gained a wider scope of understanding of deafness in Turkey through the Dear Association, although I could not carry out my initial plan to interview deaf people because of my lack of sign language skills and Havva Hanım's busy schedule.

1.4 The Organization of Chapters

To explore how mothers' role and understandings regarding deafness are shaped by both their personal histories as well as medical and social norms, this thesis proceeds as follows: The second chapter examine the main approaches and theories on disability in disability studies. I then discuss how family is situated within this literature, with a focus on families' transforming roles and their take on medical approaches. I concentrate not only on works that lay out the experiences of family, but also the strategies that family deploys in their everyday lives, including advocacy work. I then move on to discussions the deaf studies literature, which was the theoretical motivation for me to examine deafness in Turkey.

In the next section, I review the discussions and the scholarly work on deafness and deaf individuals in the context of Turkey. I then narrow down the scope of this thesis to the conceptualization of family in Deaf Studies, especially on works that focus on families' experiences in controversial debates about cochlear implants.

The third chapter is centered around fieldwork findings. By focusing on the medical, rehabilitative treatments and schooling processes that mothers with deaf children delve into, I first explore how mothers make sense of deafness. Second, I investigate how their experiences also create new practices and notions of mothering in relation to the medical and social worlds of deafness. The first part of the chapter examines mothering roles and understandings of motherhood in relation to medical events such as diagnostic tests, hearing aids, rehabilitation

centers and cochlear implant surgery. The second part of the chapter discusses the education process that mothers with non-cochlear implant using children encounter. In each part of the chapter, I demonstrate how available discourses, medical practices, the lack of professional guidance and the inadequacy of sign language-based education contribute to the construction of deafness as a deficiency.

The fourth chapter focuses on how the mothers in this study translate the problems they encounter throughout medical treatments and education into demands at the Association for Families (AF). By tracing the reasons behind the organization's founding, I examine the ways in which mothers use this space as a way to both support each other in raising disabled children and to vocalize the demands that grow out of their experiences as mothers of deaf children.

Finally, the last chapter provides conclusive remarks and suggestions for further research.

Chapter 2

2. Literature Review

Impairment defines a functional condition. The notion of disability, however, is founded on the idea that impairment is an individual pathology, a condition that deviates from what is defined as "normal". Lennard Davis (2006) expresses that the notion of disability was constructed historically in the 19th century. With the establishment of statistical science, the categories of "normal" or "abnormal" and "abled" or "disabled" were defined.

As statistics identified deviations, medical science sought to cure the impaired body and approximate it to what was defined as able-bodied. This perspective is mostly defined as a medical model or individual model, which refers to "how individuals with disabilities have been categorized as 'sick' and placed under the jurisdiction of the medical establishment and medical professionals" (DasGupta, 2015, p. 341).

The disability rights movement was formed in 1960s by disabled activists in UK and US and shifted the focus to social, economic and historical conditions that disable, stigmatize and exclude the impaired body (Hughes & Paterson 1997; Thomas, 2004; Shakespeare, 2006). Emphasizing disabling conditions brought a conceptual critique to society's ableist norms, and to the medical apparatus that locates the problem within the body. This critique, in turn, created an agenda around "forms of resistance, and the struggle for bodily control, independence and emancipation" (Hughes & Paterson, 1997) that informed not only disability rights struggles, but also became the main theoretical stance within disability studies, which is called the social model.

These tenets, especially *the struggle for bodily control*, *independence* and *emancipation* determine the conceptualization of family and care in disability studies

informed by the social model. Family is perceived as an important actor that disrupts disabled family member's control and choice over his/her body (Cocks, 2000; Oliver, 1996) by engaging them with the medical apparatus. On the other hand, familial care reduces disabled individuals to "passive and dependent recipients" (Kröger, 2009, p. 399), who are controlled by their caregivers and secluded in the domestic space. Therefore, familial care leaves no room to independence or emancipation (Morris, 1997). In other words, the disability studies literature examines the ways in which both family and care reproduce hegemonic understandings of the medical model, which is built on the idea that impairment should be corrected or treated.

Although the tenets of the social model inform perspectives within disability studies and generate a critique of the medical model, prominent scholars within disability studies urge others in the field to reevaluate the dichotomy between the medical and social models (Shakespeare & Watson, 1997; Paterson & Hughes, 1999; Shakespeare, 2006). Shakespeare (2006) indicates that this binary overlooks the existence of the impairment and its lived experience: "From seeing disability as entirely caused by biological deficits, the radical analysis shifted to seeing disability as nothing whatsoever to do with individual bodies or brains" (2006, p.31). It is argued that failing to discern the corporeality of the impairment might prevent us from understanding the lived experiences of the body and what impairment brings, and instead prioritizes the "the habits of privileging performativity over corporeality, favoring pleasure to pain, and describing social success in terms of intellectual achievement, bodily adaptability, and active political participation" (Siebers, 2006, p.175). Williams (2001) in his article "Theorizing Disability" underlines that a sociological perspective could help us acknowledge that there are multiple ontologies at work that make both social barriers and impairment real:

These ontologies exist in the biomedical constructed body, in the person's relationship to the "lived" body, between the person and the people with whom he or she comes into contact, and between the historically formed society (encompassing political economy, social welfare, culture and ideology) (p. 129).

This perspective summarizes the starting point of the theoretical framework for this study. Let me elaborate on this further. Biomedicalization is the key concept here to understand how disability is experienced, managed and constituted in the context of new technologies such as the Cochlear Implant. But before narrowing down my scope to the context of disability and deafness, it is crucial to understand how new technologies and the medical processes that they generate create a new understanding of one's disability or illness.

Adele Clarke (2014) defines biomedicalization as the enhanced possibility of modifying or curing the body due to increasing technological innovations. These technologies of the medical terrain bring new social experiences and identities for the people who engage with medical diagnoses, tests and implantations. In order to underline how technological innovations shift the social and economic experiences and understandings of diseases, disabilities, and one's health and body to a new level, she states as the following:

Theoretically, biomedicalization is part of a broader shift from what Foucault (1975) termed "the clinical gaze", dominant since the eighteenth century, to what Rose (2007) calls "the molecular gaze", reformulating "vital politics" and "life itself" in the twenty-first. (Clarke, p.1)

Nikolas Rose (2007), referred to by Clarke in the abovementioned quotation, is one of the most influential scholars who conceptualizes how individuals under biomedical regimes make sense of their life and health. Rose (2007) defines individuals' engagements with themselves and with the social world around them under biomedical regimes as *vital politics*:

On the one hand, our vitality has been opened up as never before for economic exploitation and the extraction of biovalue, in a new bioeconomics that alters our very conception of ourselves in the same moment that it enables us to intervene upon ourselves in new ways. On the other hand, our somatic, corporeal neurochemical individuality has become opened to a choice, prudence, and responsibility, to experimentation, to contestation, and so to a politics of life itself. (p.8)

Rose underlines that biomedicalization generates a peculiar politics of restructuring life as a project to be enhanced, corrected and maximized. This politics also shapes modes of citizenship. The concept "biological citizenship" is coined and developed (Rose, 2007; Rose & Novas, 2002; Petryna, 2003) to display how illnesses and bodily conditions create a particular engagement with "the duties, rights and expectations of human beings in relation to their sickness, and also their life itself" (Rose, 2007, p.6). More specifically, Petryna uses this concept to show how bodies exposed to harm by the state's violations can use this harm as "something to be turned into a resource and then parceled out" (2003, p.312) in reaching the state or welfare channels.

For Rose and Novas (2003), biological citizenship is the way in which individuals engage with themselves and life by being informed on "biological images, explanations, values, and judgments thus entangled with other languages of self-description and other criteria of self-judgment" (p. 134). This engagement creates an active involvement from those "curable subjects" of biomedicalization for collaborating with medical expertise and its social reflections to align their bodies to the criteria that are defined for able-bodiedness or for being healthy. On the other hand, engaging actively within each step of the medical intervention also creates new forms of "lay knowledge" (Rose, 2007; Raz & Amano & Timmermans, 2018). This collectivity is conceptualized as "biosociality" by Paul Rabinow (1996) to underline the social communities that gather around the same bodily, genetic or biological

conditions. Sharing similar forms of knowledge and "biomedical" identities provides this collectivity for those who deal with the same diagnostic labels, illness experiences, discriminations, or battles around similar bureaucratic processes, along with similar affective responses such as hope and fear that these experiences create (Rapp, 2000; Rabinow, 1996; Rose, 2007).

Based on the framework that I have laid out here, I will examine the literature on the ways in which families engage with disability.

2.1. Family, Care and Disability

Historically, families' role and care work regarding disability are examined through a set of legal arrangements and policies by which family becomes a more apparent actor in professional systems like special education and rehabilitation (Leiter, 2004; Kelly, 2005). Family shapes the disability experience, alongside medical experts, as the main assistant to disabled children in the treatment process. In making sense of disability, families mostly adjust themselves to medical practices and discourses, seeking normalcy for their children through medically defined solutions such as rehabilitation (Bezmez&Yardımcı, 2015) and special education (Runswick-Cole, 2007).

A body of research studies why families accept diagnostic terms or medical treatment (Mckeever & Miller, 2004, Ryan & Runswick-Cole, 2008, Landsman 2009, Landsman 2005, Darling & Seligman, 2007), despite the fact that families "rarely enjoy an equal relationship with professionals, often lacking knowledge, expertise or power to influence decisions" (Brett, 2002, p. 827). This line of research argue that accepting medical treatment may not imply that families pathologize the impairment of their children. Rather, it has been argued that a medical approach is motivated by social repercussions that impaired bodies might experience in an ableist society. While families come to terms with medical treatments, they strategically use medical labels to facilitate professional care and overcome the unequal

relationship they experience with experts. Diagnosis is also strategically used by families to overcome the unequal relationship with experts. Without confronting "hesitant, blunt or vague answers to professionals" (Bosteels et al., 2012, p. 998), families accept the diagnostic terms and therefore can no longer be regarded as ignorant or incompetent. Diagnosis, in this way, provides "a medical certainty" (Blum, 2015, p. 121) and a *"label"* (Ryan & Runswick-Cole, 2008) and eases access to services, since diagnosis is the first step toward benefitting from available welfare resources, specifically rehabilitation and special education. Yet, families may also decline to use medical labels and instead use their own terms, such as "*inconvenience*,*"* to define their children's impairments (Rao, 2001).

Apart from family's understandings of disability, familial care work is also examined in the literature to understand the ways in which disability affects families. This vein of work mostly discusses the burden of care, stigma and marginalization that family experiences (Bjarnnson, 2002; Brett, 2002; Hartblay, 2012), and also attends to the coping mechanism that families develop. Here, Eva Kittay (2011), as a scholar and the mother of a daughter on the autism spectrum, underlines that disability rights activists should not overlook the importance of familial care because "the denigration of care and dependency towards an attitude that makes the work and value of carers invisible," has the effect of "creating one oppression in the effort to alleviate another" (p.51). Although demonstrating the challenges of care work is acknowledged to be important, it is argued that a narrative focused on burden is not always situated in a socio-economic context (McLaughlin, 2012; Green 2007; McKeever & Miller, 2004). McLaughlin reminds us that "we need to remember the routes through which disabled families are marginalized in society" (p.409). Without tracing these routes, she warns us, challenging care work and coping mechanisms might discriminate against families who cannot develop coping mechanisms, preventing us from examining the social determinants that leave families without solutions.

Below, I will narrow the scope of my thesis to maternal labor.

2.1.2. Motherhood and Gendered Care Work in relation to Disability

Mothers have a significant place in the scholarly work on disability and family. There, it is argued that family should not be taken for granted as a neutral entity (Ryan & Runswick-Cole, 2008; Traustadottir, 1991), since maternal labor is taken for granted as being "responsible for child outcomes, and thus for health of families, future citizens and the nation" (Blum, 2007, p.202). Leiter (2004) differentiates the practice of mothering a disabled child from the mothering of non-disabled children in two ways: "as an exception to typical care work they do, or as an extension of it" (p.837), which refers more to "a professional career than traditional mothering work" (Traustadottir, 1991, p. 217).

The emphasis on "professional career" is also underlined in other works, since medical treatments demand an intensive care work from disabled children's primary caregivers, usually their mothers. In this regard, rehabilitation is important for "involving disabled people and their families in the process, monitored across time, and outcome oriented" (Albrecht, 2015, p.424). Care work is also informed by the type of impairment: whether it is physical or intellectual, visible or invisible (Bower&Hayes, 1998). Yet, every form of impairment entails scientific and medical procedures, which demand specialized care work, as regulated and defined by experts (Malacrida, 2003, 2004; Blum, 2007; Traustadottir, 1991; Ryan&Runswick-Cole, 2008). Maternal care is refashioned in accord with these given tasks and mothers gain "special competence" (Ryan&Runswick-Cole, 2008) in specific forms of care that often belong to expert practices. Care work that is professionalized and hence medicalized also becomes prone to expert surveillance, which not only regulates but also valorizes or demonizes maternal care as "good" or "bad" (Malacrida 2004; Mckeever&Miller 2008 ; Blum, 2007). These studies further argue that mothers internalize this classification and feel themselves inadequate when they cannot adapt to these protocols.

Blum (2015) finds the roots of mothers' reproduction of disability not only in their protection of the child's personhood from disabling mechanisms. It is also associated with the norms that idealize motherhood and make mothers valuable in relation to their children: "the unruly and impaired children burden the community's resources, threatens to disrupt its sense of order and safety, and raises questions about the mother's physical, mental and moral respectability" (2015, p.21). In this sense, women's commitment to intensive medical care work is associated with not only fixing the impairment, but also fixing the devaluation of motherhood by showing their collaboration in medical treatment (Mckeever&Miller, 2004).

As I outlined in the previous section, allying with medical procedures is not an unproblematic path either for families or for mothers. As primary caregivers, women who engage with medical treatments to cure their children's impairment suffer from the lack of support both in professional and familial realms (Brett, 2002).

2.1.3. Family Advocacy on Disability

When families engage with new institutions, they also become aware of the inadequacy of existing services, and try to compensate for the discrepancy between what they need and what they get in reality (Darling&Seligman 2007). Although these activities do not necessarily aim for major societal changes, families are described as in a constant "crusadership including activities such as lobbying school officials, changing doctors and creating new programmes" (Dowling, 2003, p.882), as well as battling to overcome the stigmatization and access services (Bjarnason, 2002).

As primary carers, mothers engage with public advocacy, which might positively change their access to the services (Ryan & Runswick-Cole, 2000; Traustadottir, 1991), even in cases where they have not had prior engagement with public activism, as Panitch (2008) argues. Yet, it is important to note that mothers' engagement in the public arena is not only motivated by the limitations of healthcare services. It is also argued that "the limits of kinship

within a gendered nuclear family structure" (Ginsburg & Rapp, 2001, p.540) that fails to support women's care work pushes mothers toward activism. Drawing on the same issue, Hartblay's (2012) ethnography on the activism of two mothers of children with disabilities in a village in Russia shows that engagement with the state and civil organizations results from the absence of support in these mothers' daily lives. In a similar vein, Lewis (2016) reveals that mothers of children with rare disabilities–deafblindness–in Guetamala organized a community wherein they merge "affective experiences and political action" (p.3).

Despite this lack of support, family-based organizations and self-help groups are, to some extent, not embraced in the disability rights literature that adopts the social model. For instance, Darling (2003) draws attention to the differences between family rights activism and disability rights activism led by disabled people. Darling defines the family organizations as follows: "Their activities may include self-advocacy, as well as involvement in larger movements in order to create normalization-promoting social change" (p. 887). Darling suggests that the family reproduces disabling ideologies. Yet, Landsman (2005) responds to this critique of family advocacy work by arguing that the "social model is effective in exposing societal barriers to full participation, yet it provides parents little guidance about how to ensure that adequate social change will take place in time to positively affect their own child's life" (p.137).

As I outlined in the first section of this chapter, disability rights focuses on a struggle through which disabled people represent themselves "in accordance with their aspirations and status" (Prince, 2004, p. 465) and speak out against the marginalization and discrimination (Shakespeare & Watson, 1997). Therefore, advocacy led by non-disabled people, including family members, is often seen as disempowering and misrepresenting disabled people's life and demands (Shakespeare, 2006). Family advocacy is viewed more favorably in the literature in cases of learning difficulties that prevent disabled individuals

from advocating for themselves. Yet, Shakespeare also admits that disability rights activism often overlooks the roles of family and carers: "While accepting the importance of independent living and demedicalisation, I think there might be a danger of ignoring or undervaluing the role of parents. In stressing the negative aspect, there is a danger of giving an unbalanced picture, and failing to see all the good and hard work which parents of disabled children do" (Shakespeare, 2006, p.188). Therefore, we need to also attend to the importance of collaboration in order to overcome the inequalities faced by both caregivers and disabled children (Shakespeare & Watson, 2001).

Before I review the specific literature on the relation between family and deafness, I discuss the main tenets of deaf studies and research on the deaf community, including in Turkey, in order to provide a sense of how deaf studies emerged as a subfield and what determines its approach to the family as a social institution.

2.2. Main Discussions in Deaf Studies

Deaf Studies' main argument seeks to define deaf people as a linguistic minority, and not a disabled group. Deaf Studies as a subfield is sometimes at odds with disability studies, although each shifted its argument from the medical model to the social by paying attention to the structural sources of exclusion and stigmatization that disabled people encounter (Burch & Kafer, 2010). However, these similar paths did not bring the two areas together; on the contrary, they created a different path for deaf scholars and activists focusing on particular social problems and a particular community organized around being deaf (Padden & Humpries, 2006; Scully, 2012). Therefore, disability scholars and activists often criticized Deaf Studies' standpoint as "often benefiting from international, national and local disability laws" (Friedner, 2011, p.15), despite distinguishing themselves as a minority. Deaf activists and theorists respond this claim by suggesting that deafness historically encountered more normalization and curing processes than other disabled groups (Ladd, 2003). For

Shakespeare, the main reason behind this division is that "dominant disability rights demands – such as an inclusive education for all disabled children – are rejected by deaf communities who want their children separately educated via the medium of sign language" (2006, p. 75).

Deaf Studies theorists identify deaf culture as "those deaf and hard of hearing individuals who share common language, common experiences and values, and a common way of interacting with each other, and with hearing people" (cited in Ladd, 2003, p.41). Though the terms are not widely used, prominent Deaf Studies scholars also conceptualize the values and culture shared in deaf community as "Deafhood" or "Deaf Ethnicity" (Ladd & Lane, 2013).

One of the main institutions through which deaf people meet and by which they engender a culture within sign language is deaf schools (Atherton, 2009; Baker-Shenk & Kyle, 1990 ; İlkbaşaran, 2015; Ladd, 2003). It has been argued that sign language education has been historically marginalized with the prevalence of oralism, which was introduced as part of nation-building agenda at the end of 19th century that dominated the education of deaf people until the 1970s in the UK and US:

> The movement of pure oralism was rooted in a burgeoning nationalism that led many nations to suppress minority languages and, as well as interpretations of evolutionary theory that cast sign languages as relics of savagery, and eugenic fears that deaf marriages would lead to the proliferation of defectives (Baynton, 2015, p. 151).

It is still important to note that while schools without sign language education do deprive deaf people of educational rights, school can still engender a culture through which deaf children realize their deaf identities and communal bonds by learning or developing sign language from each other (İlkbaşaran, 2015; Baker-Shenk & Kyle, 1990, Atherton, 2009).

In this section, I examined the works and conceptualizations informed by western settings where sign language-based policies are established. Below, I discuss how deaf culture is conceptualized in different socio-historical contexts.

2.2.1. Non-Western Examples of Deaf Experiences

Deaf Studies is based on mostly western cases and conceptualizations. The prominent scholars of Deaf Studies criticized the lack of diverse historical perspective in the field, stating that "deaf cultures could not be understood in isolation from the societies in which they are embedded" (Ladd, 2003, p. 569). Criticizing the lack of empirical evidence from non-western contexts, anthropological work on deafness mostly draws attention to the diverse forms of deaf identities in other parts of the world (Fannon & Mauldin, 2016; Friedner, 2011; Nakamura, 2006). They argue that deaf culture is far from universal. Fannon and Mauldin (2016) explain that this is "…because [deaf people's] experiences are produced by a combination of their bodily status, their community membership(s) or other cultural markers, and the larger society within which they are located" (p. 215). Other examples from different geographies such as Russia (Pursglove & Komarova, 2003) and Nicaragua (Sengbas, 2003) underline *subtle* and heterogenous identity claims. Likewise, in Taiwan the choice between Chinese and Japanese sign language is used by deaf people to signify their socio-economic status (Ann, 2003). The recognition of sign language in Taiwan strengthens the deaf identity claim, even though they do not use the same "deaf" terminology as the UK or US (ibid.).

In the literature on Turkey, only scarce empirical work examine the experiences of the deaf community. Y. Kemaloğlu (2012) emphasizes that deaf schools, deaf organizations and deaf sport clubs where deaf people can gather are important institutions and organizations that allow deaf people to identify themselves as deaf and use sign language to communicate. Another study focuses on how self-identifications of deaf children vary according to their language use. Sarı (2005) identifies three groups, "Culturally Hearing identity, Culturally

Deaf Identity and Bicultural identity," in his research, which was conducted in three different deaf schools. He concludes that deaf children who use "sign language, finger spelling, gesture and mime," are more likely to self-identify as culturally deaf.

İlkbaşaran (2015) also underlines that deaf schools are important institutions, despite their oralist tradition, since deaf people can meet and sign to communicate there. She further argues the proliferation of digital technologies engage deaf organizations and sports clubs in Turkey with deaf organizations in other parts of the world, which in turn provides a stronger connection to global deaf identity.

2.2.2. Family in the Discussions of Cochlear Implant

In the Deaf Studies literature, examination of the family mostly involves the discussion of cochlear implantation, which is a highly controversial topic. Starting from the tenet that deaf culture is constructed through deaf people sharing the same cultural and linguistic conditions, there is "the recurring theme is that deaf children are not like their parents and deaf people are not like hearing people" (Friedner, 2011, p.22). Accordingly, hearing family members appear as limiting entities who prevent deaf children from participating in deaf culture by implementing medical interventions, such as Cochlear Implants (Blume, 2010; Mauldin 2012). Yet, this theorized close link between families and cochlear implantation is not empirically supported.

As I described in the Introduction, a Cochlear Implant (CI) is a technological aid that is surgically placed in the ear; after implantation, rehabilitation processes are required for the deaf person to process sounds and speak. This process is often encouraged by avoiding sign language, in order to allow easier adaptation to learning sounds (Mauldin, 2012, p. 15). The CI cannot be implanted in all deaf infants or adults. In order to have an efficacy in hearing and speaking, CI targets mostly infants because learning to hear and speak is more efficient if implantation occurs at an early age. This is why deaf culture sees CI as an attack on sign

languages and a barrier to deaf values' transmission to future generations. Therefore, family is an important in deciding for or against CI implantation, and thus is referred to as an agent that tears the deaf child from the genuine deaf community. In his book "Artificial Ear" (2010), Stuart Blume historically examines the Cochlear Implant's industrial emergence in Europe. He argues that Cochlear Implants did not speak to the needs of deaf community; in fact, CI is agonized over in the deaf community because deaf people prefer to identify themselves not as unable to hear, but as a linguistic minority. He underlines that hearing families are more attracted to it as a "cure" to make their children hear.

Besides the works on hearing families' role in CI implantation, there are also studies on families' responses to deaf culture's position. Peters (2000), in an auto-biographical article, explains the difficulty of the decision over implantation without taking sides between the deaf and hearing world, criticizing both as reducing "the arguments of the other to caricatures are hardly helpful to those of us" (p.266). Although the CI is mostly preferred by hearing families, these families are not always on the same page as health professionals (Wiefferink, et al., 2012). Mauldin's (2012) ethnography at a Cochlear Implant clinic in the United States reveals that cochlear implantation process is less than scientific. Medical professionals and parents constantly negotiate the meaning of being healthy, being deaf and being normal (Mauldin, 2012).

In this chapter, I outlined the main literature with which this thesis enters a dialogue. The next chapter will focus on mothers' experiences and their roles in medical and educational settings.

Chapter 3

3. Disabling the Deafness: Mothers' Experiences in Medical and Educational Settings

This chapter reveals how deafness is constructed and made significant as a deficiency throughout the institutional processes with which families and their deaf children engage, starting from the diagnosis of the impairment. By focusing on medical, rehabilitative treatments and following the educational process that mothers with deaf children experience, this chapter seeks to understand, on one hand, how deafness is perceived as an object of treatment and, on the other hand, how mothers adapt motherhood to caring for a disabled child by themselves and in collaboration with doctors, rehabilitation experts, teachers, family members.

Starting from their child's diagnosis, mothers find themselves immersed in the medical process. While diagnosis brings a despair, this feeling is often imbued with broader social concerns about the possible social stigmatizations deaf people or fear of not being able to respond to their children's needs. As the main caregivers, mothers find themselves responsible for providing their children with the best possible life, which, in their opinion, can be achieved through medical treatment. Yet, it is not a smooth process, or, as Mauldin (2012) argues, an "objective" one (p.46). After the diagnosis, women's access to next steps is dependent on their economic resources and the availability of the healthcare services. For instance, high prices in the hearing aid market and only a limited contribution from national health coverage make access to hearing aids difficult. Yet, women exhaust their economic and/or social resources to find doctors or to obtain the aid.

After receiving a hearing aid, children enter a rehabilitation process which entails hearing and speaking therapies. These rehabilitation services demand that caregivers participate in these sessions and maintain these therapies in children's everyday life in order

to enhance their hearing and speaking performances. This is the stage in the process where women gain new caregiving roles. Until the rehabilitation process, mothers' responsibility was dominantly related to finding the best doctors or battling for access services. While the mothers still shoulder these responsibilities, with rehabilitation they also feel responsible for enhancing their children's auditory skills; as a result, they adjust their own mothering work to match what is advised or left to mothers by experts. When mothers adapt to these demands, their care responsibility intensifies. Furthermore, the success of their children in their rehabilitation exercises becomes a criteria for determining the success of these mothers.

Similarly, the cochlear implant (CI) process also demand mothers' care work. After the surgery, rehabilitative therapies for learning new sounds continue, in addition to speech therapy. This situation, on one hand, redefines mothering in such manner that mothers' care work can enhance children's auditory skills if they work hard enough. On the other hand, the whole rehabilitation process strengthens the idea that impairment can be treated and improved. Also, collaborating with the medical treatments in order to overcome the impairment at each stage of everyday life eventually brings mothers to critical engagement with the public, if not with the medical construction of the disability. In other words, while mothers' narratives are imbued with critiques of rehabilitation services, schools and the marketization of medical treatments, their narratives also reiterate the dominant discourse of medical expertise: fixing the impairment. In this part of the chapter, I have tried to examine mothers' understandings of deafness and their changing caregiving roles in relation to medical processes.

In the second part, I will examine the same phenomena in educational processes for mothers of non-implanted children. I argue that the absence of sign language in the official education system reproduces mothers' medicalized understandings regarding deafness.

While deaf schools do not provide a sign language based education for deaf children, as the works from Deaf Studies suggest, children learn sign language from their peers whose parents or relatives are deaf. In other words, despite oralist methods like lip reading used in formal language, sign language is still very crucial in deaf children's daily lives. Yet the exclusion of sign language from official education suggests to mothers that if they let their children communicate in sign language, their children will be further marginalized in hearing society, of which mothers are also a part. Therefore, mothers concentrate on the strategies that they learned in rehabilitation process and try to implement these approaches to prevent their children's sign language use.

Starting from the realization that their children do not hear, mothers are drawn into a process in which they first try to make sense of "deafness" and then adapt to the overall practice and discourse of overcoming this impairment through medical treatment. To understand this, I begin with women's narratives on how they become aware that their child had a hearing impairment. In the following part, I move chronologically on to their experiences as they are introduced to an array of tests, hearing aids, rehabilitation centers, process of cochlear implantation.

3.1. Searching for a Reason: Making Sense of the Hearing Impairment

All the informants started the interviews by explaining how they recognized their children's impairment. All the families, except Derya's, did not have any family history of disability. As women revisited their memories, they all expressed how shocking it was when they noticed their children had an impairment. For instance, Gönül recounted:

I clearly remember when I realized a difference in Barış [Gönül's son] after his 5th or 6th month. I said there is something going wrong in him. I kept asking myself whether it was because I smoked during the pregnancy, or because of the late pregnancy. In order to

measure his reactions, I began to turn the tv's volume up and down, up and down. Barış was not responding. But back then I assumed he would be fine with a cure or with a surgery. [1]

Gönül is in her early 60s and the eldest woman among the interlocutors. She has two children. She has a daughter and a deaf son named Barış, who is 26 years old. Barış works at the IT department of a shipping firm. Gönül highlights how everything radically changed in her life when the family noticed Barış was deaf. In her own words; "the autonomy of our life has disappeared. [2]" Gönül and her husband divorced when Barış was 3 years old, since the couple could not agree on whether or not Barış should have the costly CI surgery.

The state did not cover anything related to the social services or disability treatments in 1990s. As such, Gönül's story is only a single example of how deafness was handled in the 1990s, as are Sedef's and Leyla's stories, whose children were born in the same years. Gönül, a single parent who believed Barış should get the implant surgery, could not afford the surgery expenses. She began to work as an accountant in a chemistry firm where she had worked before Barış was born in order to afford Barış's regular treatments and moved to her mother's house so that her mother could provide care when Gönül was at work.

Sedef's daughter Eda was born in 1991. Sedef was a banker before Eda was born. Eda's aunt realized that Eda reacted to television only if she saw it. Sedef explained how she felt about Eda's impairment at the time:

When Eda was two months old, she was very interested in watching TV and therefore, I did not think of any hearing impairment that she could have. But when her aunt told me that Eda does not react to sound, I began to pay attention. When I turned her back to TV, she did not react. I was asking to myself if it could be true, but I was still very sure that

she could not have a hearing impairment because neither my family nor my husband's have anyone who had a hearing impairment. [3]

In Leyla's case, her son Emir was born in 1991, in the same year as Eda. Emir's hearing is impaired due to a penicillin vaccination that accidentally scathed his hearing fibers. She explained that it was hard to admit that her son had a hearing impairment:

The penicillin impaired his hearing. But it was really hard to realize. After the vaccination, Emir's reactions became stagnant. I was working back then and my dad told me that Emir cannot hear. I was afraid that he might not hear but I did not consider that he had a hearing impairment. It is really hard to accept that there is something wrong going on with your beloved ones. [4]

These first reflections of the mothers, to an extent, are about blaming themselves and reconsidering the social and medical preferences that might have brought a disabled child into their lives. For instance, Selin reconsidered the prenatal tests she might have undergone while she was pregnant and blamed doctors for not presenting all the tests that might have informed her about Defne's hearing impairment:

We do not know if she (Defne) had a hearing loss when she was born, because back then the prenatal hearing test was not mandatory. It was only applied to the risky pregnancies of twins or if you have a kin-marriage in family history. But, I did not know such a test exists. If I knew it, I would have insisted to have it. Defne began to speak at her first year and I planned to go back to working. But she had a very severe flu and barely recovered in a month. She could not sleep when the washing machine was on, but she began to sleep. I was thinking that something is going on, but my mother said that I was overreacting; I was not convinced and went to doctor. She said there was nothing to

worry about. Finally, I took her to a university hospital and they said that I could have taken the test so that my uneasiness will cease. [5]

Selin regretted that she did not know about the prenatal test and blamed doctors for not presenting all the biomedical tests that might have informed her about Defne's hearing impairment.

Asuman's daughter Elif was born in 2000 in Adana. When she was two years old, they moved to Istanbul in order to provide a "proper" health care to Elif that they couldn't receive in Adana. Asuman described how they became aware of her daughter's hearing impairment as follows:

I was the one who realize it later. Our father (her husband) first realized it. He later told me that when he went to Elif's bed and shook the bed to control or made a noise whether Elif would wake up or not. I called our family doctor and asked if it is possible. He laughed at me and said "I guess you are looking for a fault after 19 years, there is nothing wrong. Throughout our marriage, we tried to have a baby. 19 years later Elif came and we were flying to the moon and back. So it was very hard for me to acknowledge that my baby was not like the others. I still regret that I was not the first to realize her deafness. But I am not sure whether I fooled myself or not. [6]

In accord with mothers' reflections on not considering or believing that their children could be deaf, medical doctors that they consulted also did not always consider that an impairment might be the case. They assume that children are "able-bodied" and hence find mothers delusional. When Selin and Asuman took their children to consult an expert, the medical experts assumed that their children were "in perfect health" based on a perfunctory examination.

36

The assumption of "able-bodiedness" is not evident in Derya's case, both in terms of her own recognition and the doctors', because of the genetic origin of Derya's son's hearing impairment. Derya and her husband decided to move from Erzurum when she realized Emir, her son, could not hear. Derya works as a sanitation worker in her son's deaf school and her husband works at a fence factory in Istanbul. In fact, she explained that she acted as if her son hears in order to prevent her son being a pariah as the other deaf member of their family are:

> I was so scared that my children would be deaf. My brother-in law's son was deaf and he was perished. They did not care about him, he became more and more deranged, mostly spend his days on the streets. He was abused on the streets. He took every substance people gave. I had a daughter first, and she was in perfect health. Then, my son was born. After his first months, I realized that he did not react unless he sees something. He was following my gestures but when I was not in his sight, then he was crying. At the beginning, I could not tell my parents-in-law, because I know what happened to that child. After a while, everybody understood. [7]

Instead of an unexpected impairment as the rest of the narratives, Derya denies and hides her son's deafness from other family members as "a form of coping and filtering the news" (Rogers, 2007, p.136).

Once families are sure that their children cannot hear, they enter a medical process to get a definite diagnosis, which determines their particular medical path. This process is filled with tests, examinations and measurements, as well as a sadness that an sudden diagnosis brings. Below, I will examine how families respond to the diagnosis of deafness and encounter with the medical apparatus.

3.1.2. First Reflections on Diagnosis

After the first hearing examination by ear, nose and throat specialist, infants are examined with a hearing screening test named BERA (Brainstem Evoked Response Audiometry), which is an electro-physiologic test that measures the infant's hearing impairment in decibels by sending signals to the brain. Without any hearing impairment a person could hear at 20-25 decibels, whereas a person with high level of hearing impairment could hear at 70 decibels. For the BERA test, the receiver should sleep so that the hearing threshold and the neural source of hearing loss can be evaluated. With this test, the diagnosis becomes certain. Measuring scientifically the hearing loss by this test and diagnosis means a *"tragedy"* for mothers, a designated in line with their initial reactions before the official diagnosis. These emotional responses are described as *the personal tragedy theory of disability* (Oliver, 1996), in which the impairment is seen as an individual problem that happened as a result of "some terrible chance event which occurs at random to unfortunate individuals" (p. 32).

Yet, while this certainty brings a despair, once women calculate that they should act and strategize in order to take care of their children, the responsibility of managing stigmatization and to easing the lives of their disabled children dominate. Selin describes the test process and how she felt:

We were regularly visiting the university hospital in order to schedule the BERA test. When we went there to take the test, the machine was broken; they said it was out of the order. We rescheduled a test appointment in a hearing aid center. Defne's hearing loss was in 100 decibels. Doctor illustrates the level of her hearing loss with an example: "when a plane lifts off, she probably does not realize." At this moment, I was torn into

pieces. I was in love with my husband, we had money, we had jobs, everything seemed meaningless at this moment because my life as I knew was done. [8]

Ascertaining the hearing impairment with tests brings a shattering sorrow to mothers' lives. Sedef described the process of getting used to the diagnosis of her daughter's deafness:

I fainted when they told me that my daughter is deaf. I thought that my life was slipping out of my control. I cried a lot, but I needed to make a life for my daughter. I had to move on. Immediately, I quit my job in order to take care of my daughter day and night. [9]

As seen in Sedef's example, along with sadness, the diagnosis means planning what families need to do in order to take care of the child. Therefore, in concert with taking initiatives and responsibilities, mothers calculate the economic and social repercussions that follow with diagnosis (Ryan & Runswick-Cole, 2008), including quitting their jobs to devote more time to their child. Additionally, calculations for further radical changes in their life may include "barrier removal" (ibid., p.200) to prevent stigmatization, as Derya discussed:

I was very anxious for my son because my parents-in law were very repressive about letting go of him. And back then, my husband was also under the influence of them and became angry to me because he saw my efforts as pointless. At that moment I had nothing to lose, I told my husband that I would divorce and leave him here and take the children with me. And it was not just a threat, I would have done it if he hadn't changed his mind. In Erzurum, I needed my husband because, you know, a village was a small

place, they would look hostilely to a divorced woman. But it is not like that in big cities, I thought I'd find a way to feed my children on my own. [10]

Derya assumed that she could protect her son in a big city, where she could live as a single mother. Derya's assumption that she can protect her son from a potential stigma, or Sedef's plan to organize life according to possible outcomes and procedures, demonstrate that diagnosis does not only mean despair, but also taking responsibility for "…identifying treatment options, predicting outcomes, and providing an explanatory framework" (Jutel, 2009, p. 278).

The following section is about the next step after diagnosis, where families first encounter a hearing aid – in broader terms, with medical technology. Although a hearing aid is a promising device to allow children to hear basic sounds, mothers realize that purchasing the possibility hearing aid is strictly constrained by their economic resources, because of the limited insurance contribution. Therefore, this juncture is also the point where mothers begin to develop reservations about the healthcare system.

3.1.3. Purchasing the Hearing Aid

A hearing aid is prescribed according to the BERA test results. While there is no surgery needed to use a hearing aid, it must be designed for the each individual ear. In order for it to fit the ear, a mould of the ear is taken. The sound level of the device is adjusted to the loss of decibels. Then, the hearing aid is adapted to the hearing frequencies of the deaf person. Therefore, its use requires a "tailor-made" process.[12]

---

[12] This information about hearing aid is gathered from mothers' descriptions.

Mothers' narratives show that, although it is staunchly advised to get the hearing aid immediately after the diagnosis of the hearing loss, high prices ranging from 4.000 to 10.000 TL make them an unaffordable option for many families. The device has been partially included in the Social Security Institution *(Sosyal Güvenlik Kurumu*, SSI) in 2010, which covers only 40% of the price according to the age of the hearing aid users (Aykut & Çınar, 2018). Moreover, prices can change according to the features and the brand of the device, which creates a price instability among hearing aid firms. The aid is purchased from device firms where technicians code the device according to the doctor's prescribed instructions. Selin, mother of Defne, experienced the arbitrary pricing and the implementation of the hearing centers:

We got the BERA test and then the center told us that there is no need to get an official document from the hospital and easily programed the device in accordance with Defne's needs in light of the BERA Test report. In a month, we went to the doctor and she looked at the device and said it was adjusted all wrong. We needed a new one. I called the center to return the device but they did not accept it. Apparently, we signed a contract and accepted their terms. This time, I told the doctor to write a report so that I could show evidence to the center. But instead of writing, she insisted on another brand. Just like pharmaceuticals, the hearing aid companies give commissions to doctors. [11]

The variety of the prices is a serious problem for the families who can afford the aid. But for Derya, even taking her son to a hospital became a problem:

I was already late (for the hearing aid). Therefore, I started to ask doctors in Erzurum about for where to go in İstanbul. We came to Kadıköy to a hospital. They said that the child should wear a hearing aid. It was 1.000 TL (in 2006). You are right, but how can I

purchase it? I have been consulting hospitals, municipalities, there is no hope. A year has passed. Then a doctor sent us to a municipality. We share the price as 1.000-1.000. Oğuz wore the device. But the first night he had fever. Later, I couldn't find that doctor, but a new doctor examined him and said the device was actually not fitting his ear. My son suffered a lot from the aid and he has not used it ever since. [12]

Economic resources are decisive in this process. Regardless of mothers' efforts, the process reproduces inequalities (Huiracocha, Brito et.al, 2015). By purchasing the hearing aid, families are introduced to "the particularities of local markets and care constellations, class hierarchies, social relations and family dynamics" (Hardon & Moyer, 2014, p.112).

Second, because the process of treatment is closely tied with the deficiencies in the medical services market, mothers begin to question the process. Once they manage to get an aid, a rehabilitation process including hearing and speaking therapies for getting used to basic sounds and spelling begins. In this regard, the economic and social challenges of accessing devices and the rehabilitation process, as I will examine below, create a distrust of medical procedures even as mothers cooperate with medical practices, devoting their emotional and financial resources to undo their children's deafness.

3.1.4. Rehabilitation Centers: New Responsibilities for "Fixing Deafness"

After the implementation of the hearing aid, infants proceed with the rehabilitation process. With the health report that documents the level of the hearing loss, families are directed to the Special Education and Rehabilitation Centers (*Özel Eğitim ve Rehabilitasyon Merkezleri*, SERC). SERC is affiliated with the Ministry of National Education (*Milli Eğitim*

Bakanlığı, MNE).[13] While its curriculum is dictated by the state, SERC is a private establishment that receives per-student payments from the MNE. Before starting rehabilitation, the Board of Special Education evaluates the hearing and speaking skills of the infant and prepares a "Special Education Evaluation Board Rapport." With that document, the infant is assigned to a rehabilitation center (SERC) and to free therapy sessions.

SERCs consist of a manager, administrative personnel, special education experts, and a psychologist. SERC implements the curriculum assigned by the MNE, providing consultation service to family and rehabilitation service to the infant, with the participation of family members[14]. This rehabilitation includes both individualized and group lessons to support the deaf child's school curriculum, along with hearing and speaking therapies. For the children with hearing aids and implants, speaking skills are developed through practices such as teaching the sounds of the objects, words and spelling. The centers' teachers instruct in these practices when parents are also present and expect parents to maintain these practices in their children's everyday lives.

In this rehabilitation process, the focus is on "improvement" and "progress," in which mothers, as the main carer for their child, are expected to be intensively involved. As the main caregivers, mothers' voluntarily adopt the practices of professionals into their intimate mothering labor in order to support their deaf child's treatment (Traustadottir, 1991). Yet, this adoption makes their mothering vulnerable, opening it to constant evaluation in relation to children's hearing performance.

---

[13] http://mevzuat.meb.gov.tr/html/27807_0.html
[14] https://orgm.meb.gov.tr/meb_iys_dosyalar/2017_09/19222135_RAM_kilavuzu.pdf

Mothers' narratives of rehabilitation centers focus on two themes. First, mothers are involved in this process without knowing the exact expectations. This creates an additional care responsibility for mothers, since they are expected to follow an array of ill-defined tasks that purportedly will enhance their children's performance. Second, while their children's performance is directly linked with the practices and homework that mothers should maintain, this new responsibility opens their mothering up to "surveillance" (Malacrida, 2003), through which their mothering performances are evaluated in relation to their children's hearing and speaking progress. Therefore, especially in cases when children cannot reach the "expected level," professionals' attitudes become pertinent to their mothering as "socially situated interactions that contribute mothers' feelings of inadequacy and personal responsibility" (Singh, 2004, p. 1201).

Families are involved in the education process and are expected to contribute to it. The rehabilitation process, according to mothers, is both inadequate and adds uncertainties about practices to overcome deafness by transferring the responsibility for the hearing success of the children to the performance of mothers' labor. Selin explained how she doubts whether she does the right thing:

Defne was mischievous, it was very difficult to settle her down. They teach her the words, sky, blue; tree, green, soil; plane, etc. and I take Defne to parks all the time to show her the tree, the sky. But she has been never interested in learning words or reading and she is still not. The teachers accused me of not knowing my child. Supposedly, I should have practiced at home because Defne, in their opinion, gets sidetracked quickly. I also tried to stay at home for a week, but still there wasn't any progress. You cannot see the progress that expert talked about. It was depressing and I became more aggressive when Defne could not utter the words. [12]

Mothers try to operate their actions and "personhoods" (Landsman, 2009) in line with medical processes expected from them. This, in turn, creates a feeling of inadequacy as seen in Selin's example. First, they feel their motherhood is contested and, second, they cannot be sure if they are doing the right thing to support their children's hearing and speaking. Mothers' commitment to rehabilitative practices are discussed elsewhere as a result of "mother's accurate realizations of few other choices since children were so dependent on highly complex care from multiple professionals" (Mckeever & Miller, 2004, p. 1184). Similar to Mckeever and Miller's' argument, the interlocutors of this study maintain cooperation with medical experts, implement medical practices and try to compensate any shortfall with their own solutions. For example, Gönül explained her effort to maximize her son's hearing device and compensate for the unavailability of a Cochlear Implant through exercises she tried:

At rehabilitation, the lessons were like "cat meows"; "dog barks." My son could not learn anything. So what did I do instead? For instance, when we came home from rehabilitation, I opened the closets in kitchen and asked Barış to point out to me what he ate. Did he eat beans? Chickpeas? Or, I stickered all the furniture at home. Rug, table, plate, pillow. Everything, so that he can learn at least the words. I tried to compensate the lack of special education for a child deprived of implant. I succeed a lot. I taught everything to him, not the center or the school. [13]

In case of the mothers of children without cochlear implants or hearing aids, although similar perceptions are valid, their feeling of inadequacy is exacerbated by absence of a medical technology, which eventually is supposed to facilitate "hearing."

To sum up, the experience of rehabilitation pushes mothers to critique experts and the privatization of medical services, while they also engage with rehabilitation tasks as part of their caregiving roles (Apple, 2014; Landsman 2009; Malacrida, 2004; Ryan & Runswick-Cole, 2008). Yet, their motherhood comes under a professional gaze (Malacrida, 2003, 2004), which evaluates their performances in accordance with their children's performances. At the same time, mothers also find the rehabilitation services to be inadequate. This fosters creative strategies through which mothers provide services and care on their own for their children, as seen in Gönül's example of covering everything in her home with stickers. But these strategies mostly serve the goal of becoming more efficient, as mothers seek to keep up with the practices of medical centers to undo the deafness, which eventually contributes to mothers' feelings of inadequacy. Therefore, while these narratives are imbued with a critique of social provisions and the marketization of medical institutions and treatments, they also reiterate the dominant discourse of medical expertise: fixing the impairment.

Mothers adopt new ways of integrating their care to undo the condition of being deaf, while the whole process is strongly informed by medical knowledge. This, in a short time, permeates the everyday life of families and nourishes the medicalization of deafness, especially in the Cochlear Implant phase.

3.1.5. Cochlear Implant Surgery: Expectations on "Overcoming" Deafness

A Cochlear Implant is the turning point in mothers' narratives, where the practices and discourses regarding fixing deafness culminate. The CI is implanted with the expert approval of the infant's audiological, medical and linguistic evaluation (Cankuvvet & Küçüköncü, et.al, 2012). The rehabilitation center also evaluates the performances of the infant in lessons concerning infant's response to the hearing aid. A CI costs from 20.000 to

50.000 TL and was included in the SSI in 2006, with the condition of implementing on only one ear.[15] Operation of CI relies on batteries and a cable. Although SSI partially compensates families for the CI's batteries and the cable, it does not cover the total expense of these essential accessories. For instance, SSI compensates only for one battery per day, whereas CI user need three batteries each day. Batteries cost 500-600 TL per a month and CI users can only receive 30% of these battery expenses. The cable of the CI needs to be replaced every year and costs 180 TL, but SSI gives only 35 TL for a cable renewal. Selin mocks the SSI's payment by saying that "driving to the implant store costs more than 35 TL."

Therefore, Cochlear Implants impose lots of expenses that families or the CI user pay. Hence, a CI is still a privileged technology and its availability is dependent on the economic resources of a family, although the surgery itself is now accessible. In 2010 Selin's daughter Defne and in 2007 Asuman's daughter Elif's surgeries were covered by the insurance.

While the CI is a promising technology for families, Asuman and Selin both emphasized how they searched for a doctor that they could rely on for this treatment. While they have a mistrust of doctors and rehabilitation centers due to their previous bad experiences, they saw Cochlear Implants as a reliable technology to undo the impairment, as seen in the Selin's comment:

None of the doctors seemed like experts to me after what we had been through. A friend recommended a university hospital in Ankara. It seemed impractical to me in terms of logistic reasons, but in Istanbul, I could not find any doctor I could trust. In Istanbul, we

---

[15] The recent adjustment is that the second ear - bilateral Cochlear Implant surgery is recently included to the SGK in 2016: http://www.resmigazete.gov.tr/eskiler/2016/11/20161126-13.htm. The bilateral CI aims to balance the sounds by distributing it to both ears. Also, is an option suggested by doctors for the ear, which has not been implemented yet, before it loses its decibel level for the surgery.

visited an audiologist once every two weeks and paid 300 TL, but when I called him on the phone he did not recognize me. I e-mailed Ankara and received a very caring response. We went there with my mother-in law and all doctors examined Defne very carefully and behave pedagogically. It was the first time I felt relieved after the diagnosis. They decided that Defne could be implanted and that summer (2010), we had a successful surgery. It was what I expected since I have heard the CI is the solution. [14]

CI surgeries are celebrated by mothers. On the other hand, Selin was also anxious about the surgery and possible complications. Yet, what is more worrying for her was to encounter unreliable doctors and hospitals. After the surgery, a long and laborious process begins. The device requires an intense rehabilitation process, first to process the sounds that will be transmitted through the device (Snell, 2015). In other words, "sound" is not the instant result of the CI. In addition, the difficulty of this process is exacerbated by professionals who do not transparently explain what might await CI users after the surgery (Hallberg & Ringdahl, 2004).

Selin explained Defne's rehabilitation process after the CI surgery:

After two months, we went back to special education. Defne learned words and reacted to low decibels. I understood what she was saying, but no one else could. I thought it is not normal and rehabilitation teacher blamed me for not practicing at home. She did not believe me and asked me to record our practices on camera. For her, I was not acting naturally while practicing with Defne, she told me that's why she does not speak. As a result, it turned out that Defne had also a phonological speech disorder, but the special education teacher only doubted me. [15]

CI is expected to be the last stage of the process which result in hearing. However, it requires a long process of rehabilitation regarding speaking and hearing, similar to the hearing aid rehabilitation process that I've discussed above. Having Cochlear Implant surgery is not enough to make the device function; surgery must be supported by oral practice of hearing and speaking. The involvement of the family to make Cochlear Implants effective means that a Cochlear Implant is not only a technology, but it also requires intimate care work. It is useful here to note the *technology in practice* approach discussed in Timmermans and Berg's article (2003). As they wrote:

Actually, in this approach it is difficult to single out one technology as an isolated device, because technologies are embedded in relations of other tools, practices, groups, professionals, and patients and it is through their location in these heterogeneous networks that treatment, or any other action, is possible in health care (p. 104).

CI technology intensifies mothers' care works. The cooperation of families in speaking and hearing exercises "shifts responsibility from the device to the individual" (Mauldin, 2014, p.131), requiring consistent labor and commitment from the caregivers. In this regard, the care labor of the mothers is at the center of treatment. At the same time, their caregiving becomes questionable, where "mother-valor/mother-blame" (Blum, 2007) criteria are created and evaluated, as discussed in the previous sections.

This process often encourages mothers to refrain from using sign language in order to concentrate on learning sounds and speaking (Mauldin 2012, 2014). When asked about her opinion on sign language Asuman said:

Sign language is forbidden to Elif. We have lots of kids who do not speak despite their implants. Elif was totally into sign language last year. I realized that she became reticent.

I do not accept this. She should talk and live within the society. Because we taught her to speak fluently. Most of the people do not understand that she is deaf. They think, she has only a difficulty in understanding because she only has a limited vocabulary. [16]

When children are inclined to communicate with sign language with their friends from the AF, for instance, mothers perceive it as a hindering activity, worrying that the treatment process might be disrupted. Here, it is important to recall why a CI puts family and deaf individuals at odds. The proliferation of this technology also potentially means that more of the deaf population will be targeted for this technology, thereby diminishing their culture shaped by sign language. Therefore, CI technology is strongly associated with the oppressive methods of medical regimes and has a significant place in "the politics of disability, the project of normalizing bodies, and the history and politics surrounding deaf persons and disability rights movement" (Mauldin, 2012, p.8).

The commitment to medical guidance prevails not only for parents whose children are Cochlear Implant candidates or users, but also for parents who have already eliminated the Cochlear Implant option for their children. The next part of this chapter will focus on how dominant medical discourse and oralist practices are at work in the educational setting. For families who cannot afford or do not want to get their children implanted, the medical path diverges and is shorter, although they are not exempt from medical influence.

3.2. "Integrating Deaf Children into the Society": Schooling Process of the Deaf Children and their Mothers

In this part of this chapter, I will explain what is offered to deaf children and their parents in terms of schooling once it is clear that their children will not get implanted. To comprehend the current situation, I also include a section in which I explain the

development of Turkish Sign Language (TSD) at schools in accordance with its official recognition in 2005.

The path of these families diverges from the families with implanted children. Yet, I argue that the absence of sign language in deaf school's curriculum is actually one of the factors that commits mothers to medical practices. Surrounded by the discourse and practices of medical experts and the absence of sign language in education, sign language is not available option for mothers, even though their children are fluent in sign language.

By drawing out Gönül, Derya, Sedef and Leyla's experiences as mothers of non-CI using children, I will show that ways parents follow medical advice, insisting on adopting oralist methods by which they expect to compensate for the lack of hearing. This insistence is strengthened by inadequacies of sign language-based education that parents encounter in deaf schools.

Additionally, although these mothers' children don't use CI, they all see CI as "a ticket to a normal life," in Sedef's words. This idea has its roots in the attitudes of the doctors and specialists at the rehabilitation centers toward CI. Once, I accompanied with Doruk, one of the interviewees with a Cochlear Implant, to his course at a rehabilitation center. I had the chance to meet with the rehab specialist, Filiz, who also owns the center. When I asked her about the rehabilitation process, she critically began to explain how doctors misguide parents:

There is a false guidance in our medical system. When doctors diagnose the hearing loss of a child, they talk as if there is no alternative life for deaf children except Cochlear implantation. For instance, in some cases deaf children have deaf parents and they immediately tell these parents that they should have the CI surgery and prohibit signing

to communicate with their children. What does that mean? You (the doctor) prohibit parents to have a relationship with their children. It is not something that parents can accept. Or what happens for the hearing families? You (the doctor) talk in a way that if the child will not have the surgery, their life will be destroyed. So, what happens? A process of "disabilization" *sakatlaştırma* begins for both parents and children. They feel vulnerable, do not know what to do and you (the doctor) disable the relationship between parents and their children. Everybody thinks that with an implant the deafness will be erased. The success of the implantation is seen when child begins to speak. It is seen as a medical success of implantation. No, not at all. Our medical and rehabilitation understanding is all wrong. We have to target to make these children understand, not speak. Speaking can emerge later, step by step. [17]

The "disabilization," that Filiz referrenced is experienced within the medical setting. Yet my fieldwork suggests that this process is exacerbated in the education system. Deaf schools are not designated as sign language oriented. On the contrary, they aim to maintain oralist methods, such as lip reading and spelling, and eliminate sign language so that children can focus on lip reading and speaking. Doctors advise parents whose children are not CI users to educate their children in deaf schools. Yet, the lack of sign language-based education does not provide an effective education and "the late exposure to the sign language is one of the most critical obstacles for deaf individuals in Turkey, which impacts acquisition of linguistic and cognitive skills in early childhood and perhaps throughout their lives" (İlkbaşaran, 2015, p.63). Gönül's description of deaf schools in mid-2000s supports İlkbaşaran's argument:

Teaching courses such as Turkish, Math and Science with speaking and writing on the blackboard causes poor understanding, reading and writing skills. High school level

children can barely write down their address, as a result our deaf children are seen as autistic rather than deaf. [18]

Stuart Blume (2010) in his book *Artificial Ear,* scrutinizes political, economic and social reasons that make the Cochlear Implant a success story. He also puts these reasons in a dialogue with the personal story of his deaf son and with counter arguments dominantly from Deaf Studies. Blume specifies how the Cochlear Implant becomes a symbol for fixing the impairment: "The power of medical technology is as much to do with its being a symbol of hope as with its technical effects" (p. 83).

Although CIs are perceived as *a symbol of hope* for fixing the impairment by many parents, the implication of such a technology is rather different for those parents, like Gönül, Sedef or Leyla, who lack the financial resources to have access the device. For families who cannot afford access to this technology, improvised rehabilitative exercises are still accessible. All these mothers have experience in caring for their children in their hearing aid rehabilitation process. They are used to the idea that, through medicalized exercises, they can enhance their children's auditory skills. Therefore, once they witness the unavailability of the sign language in schools, they turn first to the idea that Cochlear Implants are vital and, second, that they, as "good mothers," can ameliorate their children's impairments to an extent with hard work. Therefore, even though they have completed the formal medical process, they reproduce it through their own efforts. In other words, the mothers of children without implantation also focus on hearing and speaking in their everyday lives in order to compensate for the absence of a medical device. These mothers improvise in their own ways, under the influence of the medical approach. Some of these mothers end up applying oppressive practices to undo their children's deafness. Therefore, mothers' conduct to

normalize their children turns into oppression, or a force that eradicates deaf culture and inevitably sign language (Blume, 2010; Lane, 1991; Mauldin, 2012).

Ignoring the centrality of the sign language is not specific to mothers. They are informed on the idea of "ableism" first by the medical norms and then by major inadequacies in education which eventually put families at odds with non-medical alternatives such as sign language. Once it is clear that a Cochlear Implant is not an option for their children, mothers seek the best schooling option to "include their deaf children in the society." The education system marginalizes the deaf students at both regular schools and deaf schools. Below, I will explore families' initial encounters with the education system.

3.2.1. School Preferences of Mothers

In the following section, I will describe how the schooling process begins for families. While the dominant discourse is on the integration to society, each mother develops different strategies or undertakes new responsibilities to enter into the educational process. The children of the interlocutors, except Ufuk (18), are in their mid-20s and therefore their mothers' narratives reflect the circumstances before the legislation on sign language-based education was released or implemented.

The rehabilitation center advised me to attend to a prep school for deaf children. But I wanted my son to at least be with hearing children. I wanted him to recognize society, his peers and get used to the sounds around him. I tried to register my son in 18 different prep school. Only one of them accepted us, with the condition of a one-month trial. They told me that he could stay only if other children in the prep school accept him. Thank god, we managed him to stay there for two years until he started primary school. [19]

As seen in Gönül's story of searching for a school, once the parents have decided that they do not want or cannot afford Cochlear Implant surgery, the rehabilitation centers evaluate the hearing impairment level of the children and advise them on whether they should choose a regular or a deaf school. However, the elimination of the Cochlear Implant option does not redirect children to a sign language-based educational setting. On the contrary, ableism proceeds. Gönül wanted her son to begin at a regular prep school, in order to acclimate him to "the sounds," even though Barış could hear only very high sounds, limited to ambulance or construction noises with the assistance of the hearing aid he wore back then.

Likewise, Leyla wanted her son to integrate into society, saying that "these children cannot be stuck in the deaf schools for their whole life. They need to be in the society, they need to learn how hearing society operates. [20]" Her thought on societal inclusion dates back to her son's rehabilitation process in a university hospital, where parents are advised to register their children in a regular school in order to develop their hearing and speaking skills. She explains how she tried to find an inclusive education for her son:

We were 12 mothers from the rehabilitation class and had a very short time to find a class for our children. We decided to get an appointment from İstanbul Provincial Directorate of National Education (*İstanbul İl Milli Eğitim Müdürlüğü,* IPDNE). Our first attempt was unsuccessful, due to official's busy schedule. We didn't give up and went back there on the public day that is assigned to listen to citizens' demands and complaints. I was the spokesperson of our group and told him that we need a class to give our children a proper education and therefore we need them to show us a school and a class. I told him only to show us a class. I promised him to find a donation for the expenses to prepare the class. He interrupted me and told that they do not have the

economic and educational means for it. We thanked him and left. But we were determined to get a response and went to Governor's office. He was more open to help us and promised to schedule a meeting with the participation of an official that we spoke from IPDNE. There, I told to the official 'What do you expect us to do? Could we destroy these children all together?' His color changed and he told us in front of the governor that he will try to find a place. A week later, they told us they found a class in a public school in Aksaray. When I visited the school, I was told that they do not have any information regarding our demand. I went back to make them know that I followed the process. Only a week before the new term of the school year, we were offered this class in Aksaray and I found a volunteer who wanted to donate for a special education class. That's how we could begin formal education. [21]

Sedef also organized with the parents that she knows from the rehabilitation and registered her child in a public school in 1998. Sedef described Eda's years by saying, "There Eda learned reading and writing and also became advanced in lip reading. [22]"

Although families have a right to choose regular schools, Sedef and Leyla's narratives show that the procedure is challenging and mostly proceeds thanks to their own efforts. Connecting with people who are in similar circumstances also helps to these mothers to create an agenda to reach official authorities who might ease their access to education rights. Derya did not work back then and lived only on her husband's salary from a fence factory. Although she did not experience any difficulty in registering her son for the prep class at a deaf primary school, she could barely afford the public transportation expenses. In order to minimize the transportation costs, she would wait at the school until the school day was over. However, it is very exhausting both for Derya and Oğuz, and she decided to talk to the principle of school to find out whether she could get any help. The principle offered her

work as a hostess at the bus services so that she could bring her son to the school. While Derya expressed her happiness because of the job that she accidentally found, she continued, explaining how her happiness gave way to a despair:

My happiness lasted not too long. I told my husband that I will begin to work and he accepted. I will be always around my child and around the school. After a week, the principal called me back. He told me that I can begin to work only if I also accept work as a sanitation worker at school. He told me that they are in need of a janitor and could not afford to hire one. I was very offended. Not because cleaning is a bad job, but I was offended due to the position the principal left me in. I had no choice other than accept his terms. I began to work as a hostess and a janitor only to provide schooling to my son. [23]

Despite the principal's exploitative intentions, she explained to me that this offer gave her the opportunity to be around her son, so that she could keep an eye on her son's lessons and teachers. She explained her observations at school: "The teachers come and go, but there isn't any progress regarding the education. I cannot count how many times I made a complaint about teachers. [24]"

The entrance to the schooling process also posed challenges for other mothers. While Sedef and Leyla use their networks to access to regular education, Derya had to accept two jobs that were only paid through compensation for transportation expenses. Although Sedef and Leyla managed to register their children at first in a regular school, all the children ended up in deaf schools. Sedef explains this as a fight they knew that they will lose:

The class survived only for two years. Everything was problem in that class. After only a while in children's first year, the governor resigned and the new assigned governor did

not care for us. The teacher that they assigned for our class was a librarian and our children cannot learn what their peers learn in the first grade. We managed to survive there for two years, though, through our personal efforts. But then we were placed in a deaf school in İstanbul. [25]

Assuming that sign language will be a more effective match for Barış's cognitive skills, Gönül decided to register her son at a deaf primary school after a mainstream prep school:

I was very decisive on taking my child to a regular prep school, but I thought that primary school is another thing. How can my son learn math, Turkish? We went to check a deaf school and there was no school transportation service provided. We arranged a taxi and my son began to primary education. I was pushing myself to support my son, but we could not pass to B from A. Sign language was forbidden. I witnessed that teachers hit the children's hands so that children would not sign to communicate. Teacher wrote the courses and the instructions on the blackboard and then they tried to explain what is going on by yelling. How can children learn in this way? [26]

Both Gönül and Derya observed the inadequacies they encountered. Being in contact with principal and teachers, Gönül's tight monitoring often positioned her as a "problem parent" who is always involved in realms that are assigned to professionals:

I was always in contact with teachers. Despite my support for his courses, he could only learn basic skills. Even today, he cannot read a newspaper. He gets bored in a minute, he cannot understand. But most of teachers are not interested in them. For instance, they don't teach in sign language, yet they don't fill the absence of Turkish Sign Language (TSL) with an oral language skill. When I asked them why my son could not learn

anything, they always told me that I should be happy that my son had basic skills in writing and reading. [27]

Similar to the medical process, families learn what they should expect from schooling throughout the process. They learn how to behave, when to comply or to disobey throughout their encounters with education system as well as when they "need to become adversarial or 'difficult' with service providers in order to obtain desired services for their child" (Larson, 1998, p.867).

At first, Gönül and Asuman did not reject sign language as a communication medium . In fact, the thought of a sign language was relieving for them, once it was clear that they could not afford implantation. In this sense, they thought that sign language filled the lack of the oral language that would come with surgery and the rehabilitation. After a very short while, they realized that was is no sign language education in schools. There, they understand that deaf schools have the same perspective as the medical institutions: to eliminate sign language in order to direct children to oralist methods, even if they cannot hear or speak. Although the parents felt uncomfortable with the oralist methods such as lip reading and speaking, due to their inadequacy in teaching deaf students, they could not imagine how sign language could be an option in "real life" when it is not even an option in deaf schools. Sign language is absent from the curriculum. Yet, as I underlined, it is still present at deaf schools and is central for my interlocutors' children who are fluent in sign language. The pupils who have deaf relatives, especially deaf parent(s), teach sign language to other children at school. On one hand, the interlocutors of this study complain about the poor educational setting due to the lack of sign language. On the other hand, they also try to prevent their children from communicating in sign language, saying that "it only serves for

more isolation [28]" (Sedef). Below, I will explain mothers' approach and attitudes toward signing to communicate.

3.2.2. Mothers' Approach to Sign Language

Before the official acceptance of sign language in schools, teachers at deaf school did not use sign language-centered methods and explicitly prevented students from using it, as evident in the Gönül's example of teachers hitting students' hands. Despite these oppressive methods, all of my interlocutor's children were fluent in sign language and stopped using hearing devices after attending deaf schools. When I asked how her son became fluent in sign language, Gönül responded:

My son learned sign language from his classmates or friends from other classes and cohorts during the breaks. Deaf children from deaf families teach others how to sign. It is like a rule. And my son learned sign language in a very short period. Why? Because sign language is very natural to him. But the teachers always warned me that if he uses sign language he will not be able to learn anything. This inherently made me unhappy about my son using TSL. [29]

Deaf school provides a space where deaf children of hearing parents have a chance to engage with deaf peers by learning sign language. Accordingly, Leyla tells how her son learned sign language from his peers:

When he was attending to the special class in regular school, he did not have any clue about sign language. As he attended to the deaf school, he began to learn sign language very quickly. I know that none of his teachers know sign language and I was curious

about how he learned. He told me that his deaf friends from deaf families taught them this language. [30]

Comparing the deaf school with the regular school that Eda previously attended, Sedef indicates sign language as an obstacle to maintaining rehabilitative methods:

My daughter went backwards at the deaf school and lost every little victory that we had within the rehabilitation and special education. She learned sign language in a few months and did not want to do her speaking exercises. [31]

So, as is explicit in interviews, deaf children do not learn TSL from the school curriculum; instead, they learn it from their friends. Having learned sign language in this informal way posits deaf school in a different way than discussed in western examples, where deaf schools officially teach in sign language (Friedner, 2011).

I am interested in the lack of sign language-based education and the similarity between teachers' conduct and the approach of rehabilitation experts or doctors to TSL. Educational institutions, like medical ones, strengthen mothers' medicalized perspective by convincing them that TSL cannot be a "real language," even if it is located at the center of their deaf children's social lives, or even, for instance, as Gönül admits, if sign language is very natural to their children. Discourses and practices that discourage the use of sign language leave these families searching for medical solutions. If they are not available, parents then try to adopt oralism in their everyday life, at the expense of adopting oppressive forms or showing no effort to understand their children's communication methods. Sedef tells how she tried to prevent her daughter from signing:

For instance, spelling "k" was very tough for Eda. She could not speak this letter. She should hit her with the back of her tongue but, without hearing, she could not understand how to speak this letter. I was thinking that requires a long process and she will succeed. But as she began to communicate in sign language, a fear of losing her began. For making her feel the vibration that comes with speaking out "k," I put her tongue to her palate with a stick when we practiced. Sign language, I thought, was the reason for this decay. I was tying her hands so that she got used to lip reading and speaking like she used to do. Recalling what I did to overcome this fear, I realize I did many bad things to her. I grasp her right of living as she wants to be (crying). [32]

As is clear in Sedef's narrative, this oppressive behavior is not limited to school, but also permeates parental methods. On one hand, parents demand the eradication of social, economic and cultural barriers, in order to offer their children the same access to education as hearing children. On the other hand, they also try to erase the impairment through improvised, oppressive medical practices, insisting that it will be successful rather than accepting the socialization that deaf school brings. Landsman (2003) sees this conflictual process as part of parenting disabled children under biomedical influences:

Mothers move between these different discourses, sometimes defending the child's potential to be non-disabled against a doctor's grim prognosis of permanent disability, sometimes defending her child's right to be permanently disabled and valued in a non-disabled world. Thus, a mother stands at the center of a great paradox, saying to her child both: "I love you as you are" and "I would do to anything to change you (p.1949).

Trying to eradicate the use of sign language entails radical techniques, as seen in Sedef's narrative. Even though Gönül, Leyla and Derya did not adopt such radical methods to

prevent sign language as Sedef did, the medical approach to sign language still informed their behavior. Gönül expresses her endeavors to get her son to use oral communication:

I was trying to do his homework, I was trying to teach what he should have been taught. Therefore, sign language would mean to me to accept the mediocracy that the school tried to implement. I did everything to make him speak and categorize the sounds. I put stickers to every stuff and every inch of my apartment. I organized the whole neighborhood to communicate with him in case they saw him shopping or eating out. I forced him to communicate with bus drivers, I forced him to do the grocery shopping. Those were the things that I needed to do in order to make him an ordinary boy. [33]

Above, I discussed how mothers' approaches to sign language are shaped by not only medical institutions, but also by educational institutions which reproduce the ableist "social norms and values for behavior, feelings, physical functions, thoughts and aesthetics" (Brett, 2002, p.829). In such circumstances, mothers legitimize the use of oppressive methods in order to prevent their children from being excluded from the ableist society of which they are a part. As I mentioned, at first not every mother rejected sign language. Therefore, mothers' approach to sign language might not be static; rather, it is prone to change in relation to available discourses and practices. In the following section, I will explain the new implementations in deaf schools with the official recognition of Turkish Sign Language (TSL).

3.2.3. Promising Changes in TSL-based Education

Turkish Sign Language was officially accepted in 2005 within the Disability Code Law No. 5378. With this reform, Turkish sign language was recognized in the "Education and Training" bylaw. The explanation of the bylaw is:

By no justification the right of education of the disabled people can be dispossessed. Paying attention to the differences and special occasions, equal right of education is provided to disabled children, youngsters and adults within an integrative environments.[16]

Concerning the deaf education and education rights of the deaf people, the bylaw proceeds:

….In order to provide the education and communication for individuals with hearing impairment, Turkish Sign Language is formulated by the Turkish Language Institution. The study targeting to formulate and regulate this system is coordinated by the Turkish Language Institution and determined with the collaboration of Ministry of Education, Social Services and Child Protection Agency and Ministry of Administration of Disability.[17]

2005 could have been a historical moment for the use of sign language. However, its use in deaf schools was regulated in 2015, 10 years later. In 2015, the first national sign language grammar and dictionary book was released in order to collect the signs, which vary across cities and schools, under one framework. The main purpose of the dictionary was to collect the signs, providing a compilation of words and syntaxes for formulating a sign language-based curriculum. Concurrently, a sign language-based curriculum was released for the 1st grade at deaf primary schools in 2015. Expressing the sign language as the mother language of deaf individuals, the main purpose is defined as following:

The purpose of the Turkish Sign Language (1st Year) Curriculum is to raise individuals who improve themselves personally, socially and culturally, who are aware of their social

---

[16] http://mevzuat.meb.gov.tr/html/26139_0.html

[17] http://orgm.meb.gov.tr/meb_iys_dosyalar/2015_06/25021547_tidsozlukortaboyut_para1.pdf

and natural environment, can use what they are taught in daily life, have a high self-esteem and can use the channels for accessing information by the use of the sign language[18] (p.7).

While sign language-oriented curriculum and the creation of a dictionary are promising steps to teach children in sign language, the question of who will teach remains unanswered. Mandatory sign language courses are required in university education by the department of Education of Hearing Impairment with this regulation. Yet, teachers from various special education departments with no sign language background are still assigned classes deaf schools. I met Meryem, a teacher at a deaf school, at an event organized by the AF in a private school. She told me that she did not take any preliminary sign language classes when she began to teach in the deaf school in 2013. While she learned sign language from her deaf students, she told me that some of the incoming teachers took preliminary sign language courses, which are mostly limited to words and sentences appearing in the handbook for 1st graders.

Apart from the release of the sign language-centered curriculum, the increased public presence of sign language in media coverage has made professionals and parents more open to learn signing to communicate (Kemaloğlu & Kemaloğlu, 2012). Derya, for instance, learned sign language in 2016 at her son's school, when her son was 16 years old.

Due to the oralist educational setting they encountered in the 2000s and early 2010s, mothers are not convinced that their children can have a life with a job and education unless they receive CIs or get used to communicating orally. Leyla and Sedef still communicate with their children by lip reading. Gönül is fluent in sign language, but she still combines it with lip reading in her communication with Barış. Derya learned sign language very

---

[18] http://orgm.meb.gov.tr/meb_iys_dosyalar/2015_08/17065456_tid1.snfprog1.pdf

recently, which means that Derya and her son had a very long period without understanding each other easily. Therefore, we can argue that sign language becomes relatively more a serious option for the parents whose understandings were shaped within the oralist education. When their children were younger, a Cochlear Implant was not a device they could afford. Now, although a CI is compensated by the state, it is still not an option because their children don't want to get implanted.

Below, I will explain how Cochlear Implants still remain a symbol of "normal life," even though the children of these mothers do not want to get implanted.

3.2.4. Cochlear Implant as *a Symbol of Hope*

Although the Cochlear Implant remains desirable for parents even if they cannot access it, their children do not even consider getting implanted. When I asked the interlocutors of this study whether they would like their children to getting implanted, all of them expressed their wishes by referring to Melis, who was the first cochlear implant user in Turkey and also a member of the AF. She is a university student and is responsible for reviewing online documents in English for the AF:

When I lost my hearing with a feverish disease in 1993, my mother and father began to search for a treatment. In Turkey, doctors only told my parents that their child was deaf and could only go to deaf school and learn sign language to communicate. My parents thought that it should be the worst case scenario. My mother is a hostess, traveled a lot back then and began to search for implant. First, they found the Cochlear Implant surgery in South Africa, but it wasn't available to non-citizens back then. Afterwards they had been put into contact with audiologists from Germany and they offered to do this surgery in Turkey in order to teach to Turkish audiologists the Cochlear Implant

technology. So, I was the first Cochlear Implant user in Turkey and we could not find any state insurance or support. My mother's friends collected the surgery money for me and the doctors only charged us for the surgery, not for the cochlear implant. They gave it as a gift because I was the first one. [34]

Through her parents' social network, Melis got implanted, although she experienced the similar problems to my interlocutor's children in accessing healthcare services. Her implantation became the "good example" that mothers refer to when they explain how a technological device could have changed in their children's lives. Sedef explained:

I envy Melis. Okay, I admit that Eda and I also managed to overcome lots of difficulties, but her life would be different. She would have gone to university, she would have a proper job that she really works for. [35]

Melis's story embodies all the desires and hopes that mothers think a Cochlear Implant could provide: She fluently speaks and hears, graduated from college, has held internships and jobs. In similar vein, Gönül also refers to Melis when she talks about her son's writing and reading skills, saying "not everybody can be as lucky as Cochlear Implant users. [36]"

While parents remain positive toward the Cochlear Implant, they expressed their children are not even "bothered to consider it." Most mothers expressed that their children did not want a Cochlear Implant because they already have friends with whom they sign to communicate and spend their leisure time.

Sedef indicated that Eda is opposed to a Cochlear Implant because she doesn't like how it looks on people: "She tells me that she doesn't want an antenna on her head. [37]"

Despite their children's unwillingness attitude toward implantation, Melis's story symbolizes what Cochlear Implants means to these mothers.

3.3. Conclusion

In this chapter, I trace the chronological path that families find themselves on once they suspect that their children have a hearing impairment. Each mother agrees on how having a deaf child radically transformed their family and professional life. Regardless of whether or not their children received implants, families feel unsuccessful as hopes and anxieties around deafness evolve and turn into solid medical decisions or unfulfilled desires, in the case of not accessing medical devices such as the Cochlear Implant. Their narratives' display that before the diagnosis they were inclined to denial or self-blame for their prenatal choices. Then, diagnosis means an affirmation of deafness and, therefore, brings a "tragedy" to their life. Yet, with the affirmation of the hearing impairment, narratives suggest that a struggle for "providing best" for their children allows mothers to leave the feeling of tragedy behind.

Regardless of whether a mother has a deaf or implanted child, the Cochlear Implant lies at the heart of narratives that underline how medical process of deafness shapes family's understandings of disability and of their subjectivities as carers and assistants to treatment. In other words, medicalization permeates the everyday practice of mothers, sometimes shifting to oppressive forms, especially for those mothers whose children could not get implanted.

Deaf children who do not use Cochlear Implants are guided to deaf schools. Despite education in deaf schools, oralism is something that is constantly imposed on deaf children. Concomitantly, their parents believe that oralism is the only way for them to learn, even if they are not sure that is best for their children's educational development and well-being.

Therefore, deaf children are deprived of basic educational rights and forced to learn in a way that they cannot clearly understand. As discussed throughout the chapter, once it is suspected that they have a hearing impairment, children enter an unfamiliar medical setting that consist of new tests, devices and procedures. Introduced to a medicalized world, families are convinced that they should perpetuate these medical practices in order to overcome the child's deafness. The involvement of families in the medical and rehabilitative practice creates three major outcomes: 1) as they engage closely with the medical process where they encounter ill-defined tasks and definitions, interlocutors in this study begin to mistrust the services they received. The lack of resources, incorrect guidance and the patronizing tone that accompanied the rehabilitation process often exacerbate this mistrust and fosters a critique by mothers. 2) Managing the care work for their children at home, at rehabilitation and in the educational process gives mothers the primary responsibility of success or failure of their children's hearing and speaking performances, while the care work becomes gendered and their mothering is contested. 3) At the same time, a critique of medical procedures does not attenuate mothers' commitment to medical practices and discourses.

To sum up, I generally analyzed women's narrative about their children's treatment and education and their understandings of deafness and their changing motherhood roles in this chapter. In the next chapter, I will focus on the association that mothers formed. Drawing on their narratives, I will look at how this association provides them a space, first to support each other in mothering disabled children and, second, to vocalize similar problems that they encountered in schools and treatments.

Chapter 4

4. From Despair to Sustained Demands: An Association for Families with Deaf Children

This chapter asks how mothers of deaf children used their personal experiences to mobilize disability rights by forming a parent organization: Association for Families (AF). The Association was established in 2004, soon after Leyla, mother of Ufuk, met with Sandra by chance at the hairdresser where Leyla works. At the hairdresser Leyla learned that Sandra worked as a volunteer in a branch of an international charity in Istanbul and organized social activities for elderly deaf and hard of hearing people. Leyla asked Sandra whether she can find similar free activities where both she and Ufuk could spend time. When Sandra and Leyla found out that there were no such activities offered either by municipalities or NGOs, they decided to form a platform in which both families and children could meet and benefit from activities like swimming lessons, touristic trips and computer lessons. After a year, as new mothers and children joined the platform, the members decided to work to address the medical and social needs of deaf children. Based on their experiences, the members agreed on the particular significance of working on the medical and social needs of deaf children.

The agenda of the AF is framed by the issues that members find lacking in the treatment and educational process. Women summarize the agenda as "3E": Early diagnosis, Early education and Early Implantation (*Erken tanı, Erken eğitim, Erken cihazlanma, 3E*). For instance, the AF does lobbying work for newborn hearing tests and the inclusion of bilateral Cochlear Implant surgery in the SSI (Social Security Institution) and also collects hearing devices for those in need. Similarly, the AF reflects the experiences of deaf children's families in the official education system. They try to improve the educational alternatives for deaf children through measures such as establishing a kindergarten with adequate rehabilitation services. Additionally, they organized sign language courses and tried to revise education in deaf schools, even though sign language-related advocacy was not the focal point

of the Association. In this sense, the association provides them a *biosocial* community (Rose, 2007) in which they can mobilize to enhance the resources and rights that are offered to them and their children.

Although organized primarily by mothers, the AF also has members who are Cochlear Implant users. Through Cochlear Implant users, the Association provides a consultation network for parents or individuals who are considering a Cochlear Implant surgery but do not have enough guidance. The AF has 257 members (in 2017), including deaf, Cochlear Implanted individuals and families with children who have hearing impairments. Yet, the agenda is determined and maintained by just a few mothers and Cochlear Implant users who call themselves the "brain team." Sandra is the only woman in the AF's "brain team" who does not have any kin-based relation to deafness. Since 2016, she could not participate actively in the AF because she became the caretaker of her husband who was struck by paralysis. Her former experience and networks in civil society helped other members in AF to connect with various organizations and municipalities, and to initiate other projects such as travelling to other countries in order to observe good examples of deaf schooling. This team mostly determines the agenda, writes projects and tries to advertise the Association, while the remaining members mostly take part by asking for consultation or exchanging of information in order to learn about educational and medical reports and Cochlear Implant and hearing device options. Membership in the Association is on a voluntary basis, and the Association's expenses are funded through annual membership fees, donations and funds from events organized to raise money.

Although each woman takes part in the decision-making process, the division of labor within the Association is also set up according to women's availability. Therefore, not all mothers can contribute to the community on an equal basis due to their jobs, household works or due to the busy schedules of those who have younger children. For instance, Gönül, a

retired accountant, has, since her divorce, lived with her mother who helps to take care of her son, Barış. Sedef and Leyla quit their jobs because of their children's busy school and treatment schedules. Sedef was a banker before her daughter's diagnosis. Leyla worked in a hair dresser, where she met Sandra and she quit her job to concentrate on Barış's needs and the Association in 2004. Although Gönül, Leyla and Sedef have more time to devote to the Association, all mothers try to contribute to the Association's work. For instance, Derya works as a sanitation worker in a deaf school and in her off times she tries to cover her household work. Yet, she voluntarily takes on a "messenger" role between the Association and the school where she works. For example, she gets in contact with the Association when a family in the deaf school seeks a hearing device. Selin had to quit their job when Defne's deafness was diagnosed and tried to find a flexible job which would fit her daughter's treatment schedule. In 2014, she returned to her job in textiles as a sales representative and, therefore, she started to devote less time to the Association. Selin is highly involved in Defne's treatment and her role in the Association is to inform parents about procedures in order to enhance the process of Cochlear Implantation and schooling.

This chapter seeks to explore how disability, particularly deafness, engenders a need for solidarity for the main caregivers, particularly for mothers. Drawing on the following questions, I will try to explore how the AF offers a space in which mothers both support each other in caring for a deaf child and advocating against the deficiencies that they encounter in medical and educational settings: How do the given/available social and medical policies on deaf people lead the parents to participate in advocacy work? How does family activism serve disability rights in the context of Turkey? And, lastly, what kind of strategies do mothers deploy in order to have an influence on state institutions?

In considering these questions, I first try to explore why mothers' organizations differs from existing disability organizations. Second, I examine the similarities in mothers'

experiences that bring them together in a community. I will also discuss how the agenda of the Association is formulated over the years, as it shifted from a focus on social activities to advocacy for 3E – Early Diagnosis, Early Implantation and Early Education – *Erken Teşhis, Erken Implantation, Erken Eğitim*. Lastly, I briefly demonstrate the strategies mothers deploy to have an impact on bureaucratic channels in order to pursue their demands.

4.1. Situating Mothers' Advocacy in Disability Rights Advocacy

From the perspective of the mothers in the AF, two issues separate them from already established disability Associations. First, the mothers define the AF as a "rights-based Association that welcomes both sign language and Cochlear Implantation" whereas Association for Deaf People, in the mothers' opinion, serves only as a "social club in which the members only promote sign language and protest Cochlear Implants." Second, mothers think that their demands for the wellbeing of their children were not adequately represented in the existing disability Associations. For example, Sedef mentioned that disability Associations are bowing (in Turkish: *el pence divan*) in front of state officials rather than demanding disabled individuals' rights to education and employment.[19] The mothers saw the AF as a space which can provide room for them to fight for disabled people's rights.

As the main caregiver for their children, mothers situate most of their demands in a different position than the associations which are led by disabled individuals. Mothers of deaf children in my research delved into a process where non-medical choices are often excluded. In return this exclusion strengthens, in keeping with the ableist discourses, the idea that these children should be treated medically in order to get equal rights with non-disabled children. This position is extremely at odds with the concept of disability rights in disability studies literature, which focuses on eliminating the disabling conditions of the society instead of

---

[19] One of the reason that disability associations cannot stand as autonomous civil actors is that "it tends to avoid strong activism, which may set it against state actors, and tries to keep good relations with the latter in order to benefit from its charity and protectionist attitude in return" (Bezmez&Yardımcı, 2010, p. 604).

fixing the impairment to pursue equal citizenship rights (Rioux, 2002; Shakespeare, 2006). Therefore, mothers' advocacy work does not fit well into the "disability rights movement" framework (Panitch, 2008), since their demands are more informed by the medical authority.

Although I acknowledge the insightful arguments discussed regarding disability rights in the literature, I also find it important to examine mothers' advocacy work. As my fieldwork shows, mobilizing within the given social and biomedical frameworks is one option for mothers in order to fight for their children's rights. Excluding or dismissing the medical treatments is often not considered, since it is this social and biomedical field that mothers engage with and, therefore, in which they articulate their children's needs and their demands. In this field, mothers, who are usually the main caregivers in the families, accompany their children in every public and private setting. Inevitably, over time the mothers gain a *"special competence"* (Ryan&Runswick-Cole, 2008, 2009) in the various settings they repeatedly attend with their children in order to care for their children. As mothers keep on having similar experiences with the doctors in hospitals, or rehabilitation centers, or with the officers at the state organizations, they attain knowledge of how to manage within existing structures. Panitch (2008) refers to this phenomenon as "accidental activists," for whom mothering also means to claim rights and make demands about the field in which they are specialized.

Therefore, exploring their advocacy role is a good way to observe how they articulate their needs, problems and demands within the available familial and medical structures.

4.1.1. The Establishment of the Association: Forming a Community with Similar Experiences

The AF became one of the spaces for these mothers to act collectively in their struggles within the existing structures for their children's wellbeing. The agenda of the AF reflects the experiences of the mothers, who are the main caregivers of deaf children at home, in the hospital, at rehabilitation centers and in schools. In this section, I will explain the meanings

that the mothers attribute to their involvement in the AF community. For the interlocutors in this study, a need for a community arises due to the lack of support they experience in the abovementioned settings. Starting from the diagnosis, the lack of support in the existing institutions leaves mothers as individuals who can only access medical procedures through their own means. This, in turn, creates a challenge, especially when mothers' own social and economic resources are inadequate for the pursuit of these services. Gathering with other women in the Association and hearing similar experiences of the challenges of finding the right services makes mothers realize that these problems are not only caused by their economic status or inability to find the right services, but also by the state's indifference toward providing guidance for families. Second, taking part in a community provides them with emotional support; they can share the peculiarities of their mothering roles, which, as women state, are oftentimes underappreciated. As discussed in Chapter 3, expectations of the mothers of deaf children are in constant flux in order to meet children's medical and rehabilitative demands. As women try to adapt themselves and implement the instructions given to them to cure deafness, they feel that their mothering roles are accompanied by uncertain care roles for which they cannot get support from professionals or their intimate partners. Again, by listening to each others' stories, the gendered and changing nature of caring becomes visible and they support each other in the process of making sense of their own caregiving roles.

For instance, Leyla, one of the founding members of the AF, explained why taking part in a community was crucial for her:

Just spending one day with the families of deaf children in hospitals or schools, you realize that the state already discarded the deaf citizens. But it is my son, I cannot sacrifice him to the system. We always say that we, as families with disabilities, have no luck. But the idea of Association offered us to be our own and each other's luck. [38]

As seen in Leyla's statement, the Association serves to overcome the despair that they experience in their individual lives. This despair focuses more on the "system" than on having a deaf child; Leyla underlines that she had to act in order to "protect her son," since there is no other support system available.

Similarly, Gönül complained about the lack of state support. Gönül, one of the most active members of the Association, joined to the Association a year after its founding, in 2005. She learned about the Association from a teacher at the deaf school that her son attended back then. She had expected that the state would provide guidance to reach more accessible and adequate services:

No one around me knew anything. In rehabilitation center, I expected to find a specialist to guide me, but I couldn't. I was very fierce back then because I was the only one who supported my child. I became like a nightmare for the teachers and administrators at the deaf school. Because we (mothers of deaf children) were crying all the time at the hospital entrance, school gardens, rehabilitation centers. We were a nervous wreck. When I heard about the Association from an idealist teacher from Barış's school, I thought I could spend my energy for a good reason. I always told myself that deafness was nothing new; it existed for centuries. State was more familiar to that than I was, the state knew better than me. It could guide me, but, no. We ended up taking care of ourselves alone. [39]

Both for Gönül and Leyla, asking for better services are not new themes. Leyla mentioned how she organized public meetings to tell officials about families' schooling demands, to get an appointment with the then-Governor of Istanbul. Gönül expressed that she became a "problem parent" due to her efforts to intervene in the failing education at her son's school. Therefore, most mothers, if not all of them, are used to being in a "battle" with professionals through their individual efforts. As Landsman (1998) argues "advocacy for one's disabled child becomes part of the identity of the mother, but it is born of the recognition of the child's

humanity and of one's fear that the full value of the child is missed by others" (as cited in Brock, 2017, p. 54). What the Association brings to mothers' lives is that they acknowledge acting collectively in pursuit of enhanced services, since "individual efforts alone are not enough to effect systematic change" (Panitch, 2008, p. 3). Second, they acknowledge that the lack of structural support causes these challenges, rather than their own economic status or lack of mothering skills. Therefore, the Association presents a space where they can respond to the needs of their children collectively.

For instance, Selin came into contact with the Association when she was prescribed the wrong hearing device at the hearing aid center. Before meeting with Gönül and then other members, Selin used to think that such challenging experiences happened only to her:

> In 2010, when I had some troubles with the hearing device, I googled and found the AF. I called them and met with Gönül. She sounded so helpful because she had already been there. She calmed me down as if she knew me and invited me to the Association to meet with them. I did not know anyone who went through similar processes as I did. However, I learned that families were dealing with more severe problems in comparison to mine. [40]

Sedef joined to the Association in 2004. Sedef and Leyla's children went to the same deaf school back then, where Leyla tried to reach more families by using the school network, printing brochures of the Association to spread the word. Sedef was one of the parents who learned about Association from Leyla:

> I knew Leyla from school and we were always in contact about the problems we experienced there. When she told me that she wanted to introduce me to Sandra, I felt very happy. We lost many things because we could not benefit from technology, but I thought we could do something for the younger children. We were very lonely,

thinking that we were a few people suffering from these problems. But meeting with mothers with similar experiences taught me that I was not alone. [41]

Due to the timing of the inclusion of technological advances such as Cochlear Implants in national coverage, Sedef, just like Gönül and Leyla, could not benefit from Cochlear Implant, although she thought it vital for her child. Encounters in the Association enabled these mothers to realize that inaccessible services are a systemic problem, rather than a problem solely associated with their personal or familial economic resources. Accordingly, they tried to support each other's urgent needs.

After the diagnosis of the hearing impairment, the hearing aid is a family's most urgent need. For those who cannot afford hearing aid, the Association collaborates with various municipalities to collect and repair worn hearing aids and then distribute them to the children in need. The information about those in need of a hearing device is gathered through mothers' networks in schools. For instance, they try to be in contact with the teachers in deaf schools. Leyla explained that the Association provides hearing aids even if it does not target systematic provision:

We know that it is not like offering a kindergarden or negotiation for something to be accepted on a legal basis. But if someone needs anything, we try to respond to their needs as soon as possible. Sometimes we give our children's old hearing devices so that a more needy person can benefit. [42]

As discussed at the beginning of this section, the Association also provides a gendered space for mothers to communicate with each other about parenting a disabled child and the resulting varied responsibilities. Such caregiving is needed especially in the rehabilitation process, where rehabilitation experts demand that mothers adopt to the "teacher role" (Selin) in their everyday lives. In this process, mothering requires additional arduous work that is

expected to enhance children's speaking performances. Also, this permanent care burden duplicates when their husbands do not partake in care work.

Sedef explains how the expectations of rehabilitation process creates unequal care responsibilities in comparison to her husband:

I was so happy that I managed to find a center. At first, we went there with my husband and they told us that they expect us to attend the classes together. I nodded without any hesitation and left. On our way back to home, my husband told me that he could not attend to the classes on a regular basis. And he told me that the expenses would be for nothing because Eda won't be able improve. I understood I was all alone in my struggle. He did not attend any other meeting and I always lied when they asked about him. I always made up excuses, sometimes he was on a business trip, sometimes he was ill. How can anyone understand me? Only the mothers at the Association can understand me. Sometimes, Gönül and I make therapy sessions together, talking about our loneliness. We all have similar burdens. [43]

Sedef underlines how mothering a disabled child is different from other kinds of mothering. Sedef's point supports Mckeever & Miller's (2004) argument that mothers of disabled children do not get any credit for their mothering work from professionals or from their families. Therefore, women usually emphasize their sacrifices for their children to make their motherhood valuable. They seem to draw others' attention to their taken-for-granted caregiving, although it is a challenging work, as these women narrated. Asuman said:

We do not know how to socialize with our neighbors, we suffer when our husband invites guests. We remain very amateur in this stuff. But we are experts on hearing impairment; we do know which hospital we should go to, which reports we should reject, we know each other's problems. Therefore, we can ease each other's lives. [44]

Asuman got involved in the Association in 2007, as she tried to obtain information about Cochlear Implant surgery for her daughter Elif. Yet, Sedef and Asuman's narratives also demonstrate women's expanding roles. As discussed, the medical process demands hard work from mothers in rehabilitation as well as for finding the best doctor, best tests or best procedures for their children. This situation leaves them in a quandary, where they are both expected to perform the routine work of the household and to develop expertise on nurturing a disabled child. These multiple obligations blur traditional mothering roles.

Below, Selin states how caring eventually becomes the predominant role of motherhood as they proceed in rehabilitative therapies:

I was always questioning myself. Who was I? A mother? A teacher? I constantly interrogated my motherhood. All the friends and relatives around me seemed like they pitied me. I made myself very lonely and miserable with my own hands. And my marriage was affected. I decided to break up with my husband. Because I thought he did not help me, or do anything good for me. He dedicated himself to work since I quit my job. He worked in order to afford the needs of Defne. I knew that marrying and having a child was hard, but being a mother of disabled child was another story. I told Gönül that all these tasks were challenging for me and she advised me not to care about anyone. [45]

Selin's statement displays how she tries to function in a way to meet both the social expectations and the medical ones that are left to her responsibility. Having different knowledge compared to families with non-disabled family members, the members of AF try to adapt to *extended care work* (Traustadottir, 1991), which entails both medicalized and "natural" mothering roles toward the impaired one (Dowling & Dolan, 2001).

In fact, during the in-depth interviews, when we discussed their work and how it was different from other mothers' work, the mothers did not express a serious demand of their husbands to more equally divide labor at home. The mothers often do not hire a paid care

worker to look after their children, either. Yet, the realization of this inequality fosters the bond between mothers and makes them realize that they are not alone in the suffering that results from these uncertain roles. By talking to each other about their familial settings, women try to make sense of the mounting care work they must perform, appreciating each others' mothering which, most of the time, remains invisible.

Drawing upon the mothers' narratives, this section showed that there are two reasons why families needed to form a community around deafness: 1) The inadequacy of state and professional support leaves these mothers to engage with a complex medical and educational process through their own efforts. In such circumstances, mothers become responsible for responding to their children's needs. Being involved in a community provides them with a platform where they realize the mutual problems they face due to the limited availability of guidance from state or medical institutions. The Association offers a space where mothers can respond to and advocate around deficiencies they find in the system. (2) The Association also offers a support mechanism where members can share their personal mothering experiences, which are expanded by both the asymmetrical division of labor with their spouses and the expected roles that mothers of children with disabilities are advised to adopt by professionals. Therefore, being a part of a gendered community with similar experiences helps them to make sense of their multiple roles as carer, mother, "teacher" and wife.

The emotional support that mothers find within the AF is not directly visible in the AF's agenda. The agenda of the AF is mostly informed by what they find insufficient to improve their children's medical and social conditions. In this agenda, they paradoxically both refer to importance of sign language and to a set of interventionist procedures that are expected to fix the impairment. As stated in the introductory part of this chapter, the AF was first established to help disabled families access social activities. Accordingly, for the first few years, until 2008-2009, the organization focused on social activities such as computer lessons, swimming

lessons and rhythm workshops; then, they shifted focus to work on the enhancement of medical and social services. Below, I will first summarize the catalyst event that motivates mothers to work to address what they find missing in the social and medical resources. After describing this event, I will discuss the dominant content of their agenda, which focuses on medical and educational enhancement. This discussion will demonstrate the reasons why deaf children's mothers ended up engaging in medical, educational, and political arenas. The discussion will also detail the context in which women decide not to fight for non-medical treatments for their children.

4.1.2. The Trajectory of the Association

This section aims to reveal what mothers' deafness advocacy looks like in the context of Turkey. I will describe how the AF agenda evolved over the course of years. Then, I would like to illustrate how mothers' caregiving became a part of the medical process. I argue that mothers became a part of medical approach not only in the treatment process but also in the education process. Thus, the education and treatment-based advocacy the mothers incorporate into their agenda is also medicalized.

The transformation of the Association's agenda dates back to a social event which mothers organized in 2008 in order for their children to befriend each other. Gönül explains how they failed in socializing their children with one another:

As we organized social events, people and families got to know us. We organized a picnic and our aim was to socialize our children. But it happened to be useless. Cochlear implanted ones socialized with each other, hearing aided children were at another place and the deaf children were only with each other. It was a lesson for all of us. So, we agreed on two things. We decided to include sign language into our agenda. Most of us were opposed to sign language and many of us still are, to be honest. But we needed to do this if we wanted our children to be visible. And the second thing is, we decided to design

our agenda in a way that we could defeat the inequalities between our children. We decided to have a rights-based stance. We barely knew what disability rights entailed, but we had a sense about it because we knew what injustice meant. [46]

This event motivated mothers to work on a new agenda. After this event, the Association decided to open sign language courses especially for Cochlear Implant users and hearing aid users, so that they could communicate with sign language users. Gönül continued to explain that all hearing impaired are equal without their technological devices and therefore they should learn sign language to communicate with the sign language users "who are not as lucky as cochlear implant users" (Gönül):

I talked to other members, including Cochlear Implant users, that we have to include sign language courses into our agenda. Because deaf people also began to learn of our Association and come to ask about their report, their retirement procedures etc. I cannot say anything to mothers who do not take sign language seriously, because they communicate with their children with lip reading. But sometimes I am very angry at the Cochlear Implant users. I always tell them that they are equal with deaf people. When they take out their device, they are the same. Yet, they (Cochlear Implant users) patronize our deaf children. [47]

Gönül's anger towards Cochlear Implant users can be seen as a paradox of "double discourse of both difference and normalization" (Rapp, 2000, p.293) that mothers articulate between the dominance of biomedical knowledge and their knowledge of their children's own conditions. On one hand, mothers advise Cochlear Implanted individuals to learn sign language. On the other hand, mothers prevent their children from communicating in sign language, whether the children are implanted or not. This quandary can be seen not only in mothers' individual experiences, but also in mothers' advocacy approach, which entails both their children's difference and the medicalized understandings they reproduce in their

everyday life. Yet, as seen in this example, women do not entirely disregard sign language-based advocacy, even if it is not the main focus of the AF's advocacy agenda:

Most of our children are deprived of the right to education. The annual books distributed to deaf children from the Ministry of Education were the same as the mainstream schools. How can they expect our children to understand these long and complicated paragraphs when they do not provide education? We were the ones who endeavored to teach these complicated syntaxes. For instance, the expression *yol açmak.* Our children read it in its literal meaning. They really think that someone is trying to dig a road (literal definition of *yol açmak*). We wrote petitions to every ministry we can, we talked with the school administrations. And finally, we got a response and the school books for the deaf schools were revised (Gönül). [48]

As discussed in Chapter 3, the mothers are not convinced that schools can implement sign language education. Due to medical influences and the lack of sign language the education, they demand that their children's education is based on the oral methods advised by medical professionals. Women build an agenda which reflects their longstanding commitment to the enhancement of medical practices around three principles: early diagnosis, early education and early implantation. These principles, which are mostly expressed as 3E, aim to enhance the medical process and educational setting with oral methods recommended by the medical provision.

4.1.3. Advocacy around 3E

Although women continued to schedule social activities via the Association's network, many members started to seek medical rights that would "minimize" their children's hearing impairments. As Gönül puts it, their main agenda emerges around three conditions i.e. 3Es: Early intervention, early education and early implantation. These three principles were formulated because mothers see attention to these matters as "crucially missing," based on

their experience. They aim to establish a kindergarten in response to women's demand for early education. Newborn hearing test is an example of their commitment to early diagnosis. Lastly, early implantation concerns both hearing devices and cochlear implantation. Mothers aim to create easy access to hearing devices; they want to make Cochlear Implantation accessible, and they demand state-sponsorship of a second Cochlear Implant in every possible child.

Most women expressed that they suffered because they spent their time, emotional and economic capital on a late or wrong diagnoses. Early implantation is important because mothers emphasize that the earlier children get implanted, the better their hearing and speaking will be. Since the success in implantation of a hearing aid is inherently linked to enhanced hearing and speaking performance, early education is crucial in this process, and helps mothers meet the normative expectations for their children's hearing and speaking set by medical professionals. It is important to note that mothers' demands around 3E are in line with medical expertise. In this sense, their work is mostly focused not on challenging medical authority, but on appropriating healthcare services to benefit their children by a more comprehensive medical treatment. Gönül summarized why the agenda evolved around 3E:

We knew that government released a Disability Act in 2005. But don't assume that we were informed about the act, although we are an official Association. We learned about it from the media coverage and the panels we participated. We tried to discover whether the Disability Act covered the problems we encountered. Unfortunately, it did not. For instance, mothers could barely notice their children's hearing impairment when children are six months old. Another example was that we are all complaining about poor rehabilitation services and schools and that the diagnoses were mostly false or late. Our motto 3E has emerged like this. We say early diagnosis, early education and early implantation. Because we already lost a generation and we cannot lose any other. [49]

Gönül's statement makes it clear that the children who cannot benefit from these services are seen as a lost generation, although the Association also refers to the importance of learning sign language. For mothers, communicating in sign language means isolation from the hearing world and its opportunities. Therefore, they set up their agenda to enhance medical and educational provisions. Labeling the children who communicate with sign language as "the lost generation" symbolizes these women's attachment to medical discourses and the policies that are embodied in the 3E motto. This attachment puts mothers in a conflictual stance, where they valorize medical approaches to 'fixing' the impairment, but also recognize the importance of learning sign language. Often, the biomedical approach often takes precedence over the sign language-based policies of the AF because the former seems to be the only strategic choice to prevent other generations' exclusion from equal rights. The lobbying work focused on medically oriented programs has this aim:

> We learned that our children have hearing impairments very late. We could only learn from their indifference to voice or through inflammatory diseases. We thought that there is a mandatory hepatitis screening test for the newborns. Why not screening for hearing impairment? We had multiple visits to ministries at Ankara and sent numerous petitions to various ministries and public directorates (Gönül). [50]

Starting in 2009, as a result of the lobbying activities, mandatory hearing tests for newborns were introduced to hospitals in which 1000 or more babies are born annually. The Association also advocated that children and families should be better guided in terms of early education and early implantation. In order to propose an early education program to the government, the AF looked for good examples of education in other countries. Due to the Sandra's network in Israel, they arranged a trip to see the educational setting for deaf children there. Their plan was to establish a kindergarten in Istanbul similar to the favorable examples they reviewed and observed. Leyla stated:

The rehabilitation centers only offer 8 hours for individual courses and 4 hours for group courses monthly. It is not enough for the implanted children or children with the hearing devices. Our children need more visual materials than hearing children and therefore rehabilitation is vital to prepare them for the mainstream or the deaf schools. [51]

Gönül explained their schooling plan to resolve the early education problem:

We wanted a prep school, a kindergarten for our children. Some of us prefer mainstream school, but we are not very lucky. It is hard to find mainstream schools where they accept deaf children. So we did some research and we organized mothers to spread the news that we decided to establish a kindergarten. We had meetings with universities to find specialists on education for hearing impaired children, we had meetings with municipalities. Finally, we convinced a municipality that already had a public kindergarten to revise their facilities. We also went to university social clubs to talk with young students who raised money for us. With this money, then we had all the sound isolation and visual materials that we needed. We did our best but once the bureaucrats rotate all revisions come to a halt. It didn't last for a long time. But with this experience, we learned how to meet with schools, with officers. [52]

Although they did not succeed in establishing a permanent school, the Association provided mothers a space to use the knowledge they attained by experience in the prospective incidents that mothers may encounter. Ryan & Runswick-Cole (2008, 2009) refer to the knowledge the mothers gained through their tight engagement with medical treatment, especially in issues of education, diagnoses and devices, as "special competence." The authors also write that advocacy work "offers the mothers a sense of empowerment, of doing well and gaining a positive outcome out of what had been an often negative life experiences" (ibid., p. 51). The authors' argument is in line with the way Gönül notes the positive side of the mothers' interactions with state organizations, even if they fail to achieve their goals.

Similarly, one of the most prominent lobbying efforts of the Association concerned the inclusion of the bilateral Cochlear Implant surgery in SGK. This demand was mostly formulated in the context of Selin's experiences with her daughter Defne. The doctors told Selin that Defne could also have an implant to her other ear, which is not usually implanted. Selin told me how it was challenging to find a resource to have the second implant surgery. Her husband also quit from his job in the same period and therefore they could not afford the surgery. She told me how she initiated a campaign through Change.org in 2012.

Selin initiated first an online campaign and then a lobbying effort for the bilateral cochlear implant surgery for her daughter. Although her attempts succeeded in the long term, she underlined that her efforts for Cochlear Implant surgery should benefit every family who might consider the bilateral cochlear implant surgery. Despite the fact that she initiated this campaign and the lobbying efforts to find a resource for Defne's expenses, she expresses that she decided to afford Selin's expenses after a short while that her husband found a job. Due to the long process of this public campaign and lobbying efforts, she underlined that she was afraid of being late for Defne. Selin's individual medical struggle was not an issue discussed in the Association. Yet, being involved in such a community provides mothers a space where they can act not only on behalf of their children, but also for every person who needs similar support.

In this section, I explained the most important lobbying activities of the Association. These activities are the examples of how mothers and their children's needs are shaped within the medical paradigm in which they are embedded and how they try to pursue the demands that arise from these needs. Most of this advocacy work entails lobbying and communicating with state officials. In order to overcome barriers, my informant mothers developed strategies to communicate with bureaucratic channels.

4.1.4. Talking to the State

Lobbying work involves an interaction with state officials. Mothers told me that their former careers helped them a lot with talking with state officials. As Gönül explains:

I was an accountant, so I was familiar with official petition formats as well as speaking with official authorities. Yet, I learned a lot. Now I know which directorate or ministry I should send a petition to, but previously I had no clue. For instance, we tried to find the right entity to send a petition for a long time. But if you do this, your petition will be sent to various directorates and you ended up in an endless pending. So, we learned our lesson. We learned to send to 16 ministries all at the same time. [53]

Mothers, as a result of lack of access key figures, learned to take care of their own business "where information and expertise are difficult to locate, fragmented among many narrow specializations, or 'secret' within constrained and opaque bureaucratic offices" (Blum, 2015, p. 395). Gönül continues to talk about how, as they find strategies to interact with the state, they also find the "right tone" to have an influence on institutions:

If you write formally, no one takes you seriously. Because real experiences evaporate in this kind of speech and lose its effect. We learned to write about our experiences with our own words and our own critique. We have an order now. We first write the regulations, we then move to the inadequate or missing parts in the implementation of regulations by recounting our own experiences. Because we know better and therefore we should underline our experiences. We do not write adulatory and we do not write short. We write long and sincere petitions. For instance, I once wrote a long petition about what was missing in the education. An official from the Directorate of Special Education from Ankara called me at 19.00 and told me that he really wanted to listen to me if I had time. We had a 45 minute long conversation in which almost only I talked about our unresolved problems. [54]

While mothers formulate their actions around their personal experiences of their children's hearing impairment, they see these problems as shared by other families. In other words, these mothers "learned the power of speaking from experience and, as such, they offered a challenge to bureaucratic and medical forms of knowledge" (Panitch, 2008, p.8) as well as pointing to structural problems they observe from their own experiences. These actions render them as advocates for the needs arising from hearing impairment, if most of their agenda is around medical demands.

Women also learn to challenge the bureaucracy itself, as Panitch states. Leyla tells how she argued with an officer about a timing problem at the national high school entrance exam in 2005:

I knew that there is no additional time recognized for deaf children. The additional time is only recognized for the visually or physically impaired ones. Only to vocalize this problem to wider audiences, I invited the press to the exam and told them that the audiological impaired children are exempt from this right. After the weekend, I wrote state institutions and presented the news report as additional evidence. When they invited us to Ankara, the official told me that we tried to compare Mercedes and Murat 124 in the same pot. He told us that the additional timing would not change anything. I also knew that we needed broader changes like a visual exam questionnaire or a sign language translator. But I got so mad at his answer, so I sent his answer to a few columnists. One columnist denounced this shameful response and the official was transferred to another position. Even though we could not manage to solve our problem, we managed to subtract one useless official. [55]

In order to transfer their advocacy experiences to new members, Sedef explains how they organize meetings with new members:

At first, we share our experiences as members of the Association. We tell new members that they should not hesitate to speak up about their experiences when they interact with public institutions and doctors. We tell them that institutions are for serving us, not intimidating us. We advise them to write about every injustice they encounter, we tell them to follow their actions. We tell them how we also began from zero and got to the point of reading the official gazette on a regular basis. [56]

Speaking through their own personal experiences, mothers in the Association learn to pinpoint the structural problems and deficiencies in the healthcare services that affect their experience of the process. Selin told how getting involved in a community helps her to formulate her needs:

Before getting involved with mothers in the Association, I also knew that I had rights to ask for better medical and social opportunities. Yet, I did not know how to speak out my rights. I felt always intimidated to speak out, thinking it would diminish the limited provisions that Defne could get. Now, I know how I can formulate my sentences with a tone that is not rude but also not feeling intimidated by others. [57]

Learning "how to speak out" or "not being/feeling intimidated by state institutions" display mothers status as active agents who translate their experiences and knowledge about deafness and include their experiences in the petitions and meetings with state officials.

4.2. Concluding Remarks

In this chapter, I first explored why the women in this study are in need of a community. Being involved in a community whose participants have similar experiences mitigates the lack of support that women experience in various settings. Despite the fact that women in this Association do not totally exclude the enhancement of the sign language-based education in deaf schools, they articulate their agenda mainly around the medically-oriented policies, such

as "3E" or distributing hearing aids for those in need. The agenda of the Association focuses on the need to maximize efficiency in undoing hearing impairment. In order to pursue these goals, women also engage in bureaucratic interactions. Although interacting with bureaucracy is an unfamiliar practice for them, they use strategies like voicing their own experiences and adapting skills derived from their former or current careers. As a result, women in this study can be seen as "accidental activists," as Melanie Panitch (2008) describes mothers' involvement in public advocacy through experiences with their disabled children.

The advocacy of my informant mothers evolved around the medical and educational needs of their children. Although the women expressed that their practices entail "both sign language and Cochlear Implants," it is still hard to evaluate whether mothers' actions and demands can fit such range. Yet it is also hard to evaluate families as a mere ally of the medical expertise. As I outlined in the Introduction section of this chapter, caring for the impaired body has different implications from standard mothering work. Mothers delve into the medical realm starting from their child's hearing impairment diagnosis and from these experiences they think that the best approach is to try to cure deafness. This decision is also strengthened by the limitations that they encounter in deaf schools. Yet scarce resources disrupt the progress that they expect to have in the medical setting. In mothers' view, this makes the lack of healthcare services the main reason for not achieving efficient treatment for the hearing impairment. And thus, mothers' demands target increasing access to medically-informed policies.

My aim is not to embrace or to underestimate the advocacy practices of the women in this study. Acknowledging mothers' demands and impulses in Turkey in the 2010s gives us insight about what disability-focused advocacy looks like for mothers, to what extent and how they are politicized as non-disabled people, and how this role is imbued with both emotional and professional challenges they have encountered.

Chapter 5

5. Conclusion

This thesis examined the experiences of mothers with deaf children in Istanbul. First, I analyzed how deafness is constructed by mothers as a deficiency that prevents their children from getting equal opportunities as hearing children. Second, I suggested that these experiences display a microcosm of mothers' never-ending struggle to adjust their economic and emotional resources and their maternal labor to their role as their children's main caregiver.

The welfare regime and moral and cultural traditions in Turkey imagine mothers as the main actors of social reproduction. In chapter three, by chronicling mothers' experiences in diverse educational and medical settings, I explored how deafness is constructed as a disability. Adopting a relational approach, I examined how giving birth to a child with a hearing impairment changes those mothers' social world in terms of affections, procedures and new mothering roles. In other words, while they make sense of deafness as a deficiency, deafness expands their mothering roles to include the responsibility for "fixing" their children's impairment. Although new mothering roles are created in a multi-actor field of medical and rehabilitative experts, teachers, family members, and healthcare providers, mothers are by no means passive actors in this process. Rather, they are active agents who try to develop strategies to combat healthcare providers as well as political authorities and to adjust their resources and skills to become "that mother" who provides "the best life" to her children.

The caregiver roles of mothers whose children benefit from rehabilitation services and Cochlear Implantation are especially modified. They are expected to monitor their children's hearing and speaking performances and train their abilities based on vague instructions from

experts. As mothers try to equip themselves with new medical skills to mitigate their children's impairment, these, in turn, transform their motherhood in the sense that their motherhood practices now can be evaluated and criticized in relation to their children's hearing and speaking performances.

As I underlined in the third chapter, the evaluation of mothering is intensified by rehabilitative services and medical technologies. Medical treatment, starting from the diagnosis, channels mothers – regardless of whether their children are implanted or not – into a medicalized perspective according to which mothers try to compensate for the lack of a medical device or try to maximize the efficiency of the device though their efforts to make their children hear and speak.

This commitment appears especially in the schooling process when their children are introduced to sign language via their deaf peers. At this stage, mothers try to prevent their children from learning sign language from their non-hearing peers or their parents. This is because mothers are afraid that their children will lose interest in speaking and hearing therapies if they learn sign language. For instance, Sedef tries to make her non-implanted daughter Eda speak the letter "k" phonetically correctly. Gönül and Derya do not consider teaching sign language to their sons until their late adolescence.

Regardless of mothers' school preferences, we see that each mother exhausted their resources and networks, pushing official channels and negotiating to find a way to register their children in schools. Yet, each mother, except Asuman and Selin whose children are implanted and therefore attend a mainstream school, find the education inadequate. They all find that deaf schools do not provide any chance at university education for their children. By discussing their schooling experiences, I demonstrated how the poor educational setting heightens the treatment-based demands of mothers and their disbelief that the deaf education can be enhanced.

Throughout this thesis, I explained that welfare and medical mechanisms generate the way deafness and motherhood are articulated. Yet, it is precisely these mechanisms that generate mothers as subjects who are the main caregivers and who gain in-depth knowledge about the malfunctioning of medical and educational services. The fourth chapter is built on how mothers come to feel entitled to transform their problems with the system into sustained demands. The Family Association is an example of mothers' mobilization to reshape social policies, and generating collective solidarity as they deal with the burden of having a disabled child. The advocacy work of mothers mostly targets medical policies and aims to expand the scope of the healthcare services for disability. The activism is mostly driven individually by members. For instance, Selin's fight for bilateral Cochlear Implant surgery is thoroughly motivated by her daughter Defne's own needs. Yet, as a part of a community, the encouragement of mothers' individual efforts can bring resolutions for many families who are in need of the same services but do not have the means to vocalize this need.

These medically-driven policies have been criticized by some works in the disability rights literature. This thesis underlines the importance of unfolding mothers' politicization processes, despite the fact that their practices do not converge with the social rights perspective. I think that mothers also believe that their children should be independent and have full access to society. Yet, they also believe that this liberation will come through medical treatments. They do not want their children to integrate into society as deaf individuals, but as "corrected" hearing individuals. Mothers thus become important actors who reproduce normalization. However, this thesis does not aim to judge mothers as good or bad. Rather, this thesis prefers to display how the needs and demands attached to deafness make and are made through economic, moral and political logics of medical and welfare mechanisms.

Mothers' experiences show us that providing medical treatment for their deaf children is a more practical solution than changing the whole educational system or challenging the dominance of ableism in society. Therefore, this analysis of mothers' activism reveals that being the primary caregiver differentiates mothers' activism from the disability rights activism of disabled individuals. It gives us hints as to what structural changes should be undertaken in order to reach a more de-medicalized or democratic policy agenda regarding disability.

As I indicated in the Methodology section of the thesis, my aim was to conduct multi-sited research to understand how deafness is experienced as a biological condition on one hand, and as care work by family members on the other. My inability to obtain the perspectives of deaf community is one of the limitations of this study. If I could include deaf community in this thesis, I could have grasped how policies at the state level and ableist discourse at the societal level shape their experiences. For further research, I propose to include deaf individuals' experiences. In such extended research, we could comprehend how these diverse experiences create two different forms of communities and activisms with different sets of understandings of deafness, educational rights claims, healthcare and medical demands in the context of Turkey.

REFERENCES

Acar, F. & Altunok, G. (2013). The 'Politics of Intimate' at the Intersection of Neo-liberalism and Neo-Conservatism in Contemporary Turkey. *Women's Studies International Forum,* 41(1), 14-23.

Albrecht, L. G. (2015). Rehabilitation. In R. Adams, B. Reiss & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 420-426). New York: New York University Press.

Angrasino, M. (2006). *Doing Cultural Anthropology: Projects for Ethnographic Data Collection*. Illinois: Waveland Press, Inc.

Ann, J. (2003). The Chiying School of Taiwan: A Foreigner's Perspective. In L. Monaghan, C. Schmaling, , K. Nakamura, & H. G. Turner (Eds.), *Many Ways to be Deaf: International Variation in Deaf Communities* (pp. 230-249). Washington DC: Gallaudet University Press.

Apple, D. R. (2014). Medicalization of Motherhood: Modernization and Resistance in an International Context. Journal of Motherhood Initiative for Research and Community Involvement, 5(1), 115-126.

Atherthon, M. (2009). A Feeling as much as a Place: Leisure, Deaf Clubs and the British Deaf Community. *Leisure & Disability*, 28(4), 443-454.

Aykut, C. N. & Çinar, M. (2018). Erken Çocuklukta İşitme Cihazı Uygulamaları ve Ebeveynler. *Erken Çocukluk Çalışmaları Dergisi,* 2, 414-417.

Baker-Shenk, C. & Kyle, J. G. (1990). Research with Deaf People: Issues and Conflicts. Disability, Handicap & Society, 5(1), 65-75.

Baynton, D. (2015). Deafness. In R. Adams, B. Reiss & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 147-154). New York: New York University Press.

Berg, M. & Timmermans, S. (2003). The Practice of Medical Technology. *Sociology of Health & Illness,* 25(3), 97-114.

Bezmez, D. & Yardımcı, S. (2010). In Search of Disability Rights: Citizenship and Turkish Disability Organizations. *Disability & Society,* 25(5), 603-615.

Bezmez, D. & Yardımcı, S. (2015). Social Experiences of Rehabilitation: The Role of Family. In T. Shakespeare (Ed.), *Disability Research Today: International Perspectives* (pp. 9-27). London: Routledge.

Bjarnason, S. D. (2002). New Voices in Iceland: Parents and Adult Children: Juggling Supports and Choices in Time and Space. *Disability & Society,* 17(3), 307-326.

Blum, L. (2007). Mother-Blame in the Prozac Nation: Raising Kids with Invisible Disabilities. *Gender & Society,* 21(2), 202-226.

Blum, L. (2015). *Raising Generation Rx: Mothering Kids with Invisible Disabilities in the Age of Inequality.* New York: New York University Press.

Blume, S. (2010). *Artificial Ear: Cochlear Implants and the Culture of Deafness*. New Brunswick: Rutgers University Press.

Boostels, S., Van Hove G. & Vandenbroeck, M. (2012). The Roller Coaster Experiences: Becoming the Parent of a Deaf Child. *Disability and Society,* 27(7), 983-996.

Bower, M. A. & Hayes, A. (1998). Mothering in Families with and without a Child with Disability. *International Journal of Disability, Development and Education,* 45(3), 313-322.

Brett, J. (2002). The Experience of Disability from the Perspective of Parents with Profound Impairment: Is it time for an alternative model of disability?. *Disability & Society,* 17(7), 825-843.

Brito, L., Blume, S., Clavijo, R., Huiracocha K., Huiracocha, L. & Perez, E. M. (2015). 'Su guagua no escucha nada': Ecuadorian Families confronting the Deafness of the Child. *Disability & Society,* 30(4), 556-568.

Brock, M. A. S. (2017). *The Experiences of Women who Mother Children with Disabilities: Maternality, Relationality, Subjectivity*. (PhD Dissertation), University of Sydney.

Burch, S. & Kafer, A. (2010). *Deaf and Disability Studies: Interdisciplinary Perspectives*. Washington DC: Gallaudet University Press.

Chang, G., Glenn, N. E. & Forcey, R. L. (1994). Mothering Ideology, Experience, and Agency. New York: Routledge.

Clarke, A. (2014). Biomedicalization. In W. C. Cockerham, R. Dingwall, and S. R. Quah (Eds.), *The Wiley Blackwell Encyclopedia of Health, Illness, Behavior, and Society.* John Wiley & Sons.

Cocks, A. (2000). Respite Care for Disabled Children: Micro and Macro Reflections. *Disability & Society,* 15(3), 507-519.

Darling, B. R. (2003). Toward a Model of Changing Disability Identities: A Proposed Typology and Research Agenda. *Disability & Society,* 18(7), 881-895.

Darling, M. & Seligman, B. R. (2007). Ordinary Families, Special Children: A System Approach to Childhood Disability. New York: The Guilford Press.

Dasgupta, S. (2015). Medicalization. In R. Adams, B. Reiss & D. Serlin (Eds.), *Keywords for Disability Studies* (pp. 341-346). New York: New York University Press.

Davis, L. (2006). Constructing Normalcy: The Bell Curve, the Novel, and the Invention of the Disabled Body in the Nineteenth Century. In L. Davis (Ed.), *The Disability Studies Reader Second Edition* (pp. 3-17). New York: Routledge.

Dowling, M. & Dolan, L. (2001). Families with Children with Disabilities – Inequalities and the Social Model. *Disability & Society,* 16(1), 21-35.

Fannon, T. & Mauldin, L. (2016). "Sociology of Deafness: A Literature Review and Disciplinary History" in Sociology Looking At Disability: What did we know and When did we know it. *Research in Social Science and Disability*, Vol (9), 193-225.

Friedner, M. (2011). *"Future Life How?": The Making of Deaf Sociality and Aspiration in Urban India*. (PhD Dissertation), the University of California, Berkeley.

Friedner, M. (2012). *Parents of Deaf Children with Cochlear Implants: Disability, Medicalization and Neuroculture*. (PhD Dissertation), The City University of New York.

Ginsburg, F. & Rapp, R. (2001). Enabling Disability: Rewriting Kinship, Reimagining Citizenship. *Public Culture*, 13(3), 533-556.

Ginsburg, F. & Rapp, R. (2013). Disability Worlds. *Annual Review of Anthropology,* 42, 53-68.

Green, E. S. (2007). "We're tired not sad": Benefits and Burdens of Mothering a Child with a Disability. *Social Science & Medicine,* 64(1), 150-163.

Hardon, A. & Moyer, E. (2104). Medical Technologies: Flows, Frictions and new Socialities. *Anthropology & Medicine*, 4(21), 107-112.

Hartblay, C. (2012). *Accessing Possibility: Disability, Parent-Activists and Citizenship in Contemporary Russia*. (Master Thesis), University of North Carolina Chapel Hill.

Hughes, B. & Paterson, H. (1999). Disability Studies and Phenomenology: The Carnal Politics of Everyday Life. *Disability & Society*, 14(5), 597-610.

Hughes, B. & Paterson, K. (1997). The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment. *Disability & Society,* 12(3), 325-340.

Humphries, T. & Padden, C. (2006). *Inside Deaf Culture*. Massachusetts: Harvard University Press.

Ilkbaşaran, D. (2015). *Literacies, Mobilities and Agencies of Deaf Youth in Turkey: Constraints and Opportunities in the 21st Century*. (PhD Dissertation), University of California, San Diego.

Ilkbaşaran, D. & Taşçı, S. (2012). *Ideology and Language in the Early-Republic: A history of Deaf Education in Turkey*. Proceedings of the International Symposium on Language and Communication: Research Trends and Challenges (ISLC). Erzurum: Mega Press.

Jutel, A. (2009). Sociology of Diagnosis: A Preliminary Review. *Sociology of Health & Illness*, 31(2), 278-299.

Kelly, E. S. (2005). "A Different Light": Examining Impairment through Parent Narratives of Childhood Disability. *Journal of Contemporary Ethnography,* 34(2), 180-205.

Kemaloğlu, K. & Kemaloğlu, Y. (2012). The History of Sign Language and Deaf Education in Turkey. *Kulak Burun Boğaz İhtisas Dergisi,* 22(2), 65-76.

Kemaloğlu, P. Y. (2012). Türkiye'de Sağır Sporunun Toplumsal Analizi. (PhD Dissertation), Marmara University.

Kılıç, A. (2008). The Gender Dimension of Social Policy Reform in Turkey: Towards Equal Citizenship? *Social Policy & Administration,* 42(5), 487-503.

Kittay, F. E. (2011). The Ethics of Care, Dependence and Disability. *An International Journal of Jurisprudence and Philosophy of Law*, 24(1), 49-58.

Korkman, Z. (2015). Blessing Neoliberalism: Economy, Family, and the Occult in Millenial Turkey. *Journal of the Ottoman and Turkish Studies Association*, 2(2), 335-357.

Kröger, T. (2009). Care Research and Disability Studies: Nothing in Common?. *Critical Social Policy,* 29(3), 398-420.

Ladd, P. (2003). *Understanding Deaf Culture: In Search of Deafhood*. Ontario, Multilingual Matters Ltd.

Ladd. P. & Lane, H. (2013). Deaf Ethnicity, Deafhood, and Their Relationship. *Sign Language Studies*, 13(4), 565-579.

Landsman, G. (1998). Motherhood in the Age of "Perfect" Babies: Mothers of Infants with Disabilities. *Signs,* 24(1), 69-99.

Landsman, G. (2003). Emplotting Children's Lives: Developmental Delay vs. Disability. *Social Science & Medicine,* 56(9), 1947-1960.

Landsman, G. (2005). Mothers and Models of Disability. *Journal of Medical Humanities,* 26(2-3), 121-139.

Landsman, G. (2009). *Reconstructing Motherhood in the Age of "Perfect" Babies*. New York: Routledge.

Lane, H. (2006). Construction of Deafness. In L. Davis (Ed.), *The Disability Studies Reader: Second Edition* (pp. 79-92). New York: Routledge.

Larson, E. (1998). Reframing the Meaning of Disability to Families: The Embrace of Paradox. *Social Science & Medicine*, 47(7), 865-875.

Leiter, V. (2004). Dilemmas in Sharing Care: Maternal Provision of Professionally driven Therapy for Children with Disabilities. *Social Science & Medicine,* 58(4), 837-849.

Lewis, E. (2016). A Death in the Family: Activism, Mourning, and Diagnostic Kinship. *Disability Studies Quarterly,* 36(4).

Malacrida, C. (2003). Cold Comfort: Mothers, Professionals and ADD. Toronto: University of Toronto Press.

Malacrida, C. (2004). Medicalization, Ambivalence and Social Control: Mothers' Descriptions of Educators and ADD/ADHD. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine,* 8(1), 61-80.

Mauldin, L. (2014). Precarious Plasticity: Neuropolitics, Cochlear Implants and the Redefinition of Deafness. *Science, Technology & Human Values,* 39(1), 130-153.

McKeever, P. & Miller, K. (2004). Mothering Children who have Disabilities: A Bourdieusian Interpretation of Maternal Practices. *Social Science & Medicine,* 59(6), 1177-1191.

McLauglin, J. (2012). Understanding Disabled Families: Replacing Tales of Burden with Ties of Interdependency. In A. Roulstone, C. Thomas and N. Watson (Eds.), *Routledge Handbook of Disability Studies,* (pp. 402-416). London: Routledge.

Miles, M. (2009). Deaf People, Sign Language and Communication, in Ottoman and Modern Turkey: Observations and Excerpts from 1300 to 2009. Retrieved from: https://www.independentliving.org/miles200907.html

Miller, T. (2005). *Making Sense of Motherhood: A Narrative Approach*. Cambridge: Cambridge University Press.

Morris, J. (1997). Care or Empowerment? A Disability Rights Perspective. *Social Policy and Administration,* 31(1), 54-60.

Nakamura, K. (2006). *Deaf in Japan: Signing and Politics of Identity*. Ithaca: Cornell University Press.

Oliver, M. (1996). Understanding Disability from Theory to Practice. New York: Macmillan Education.

Panitch, M. (2008). *Disability, Mothers and Organization: Accidental Activists*. New York: Routledge.

Peters, E. (2000). Our Decision on Cochlear Implant. American Annals of the Deaf, 145(3), 263-267.

Petryna, A. (2003). *Life Exposed: Biological Citizenship after Chernobyl*. New Jersey: Princeton University Press.

Prince, J. M. (2004). Disability, Disability Studies and Citizenship: Moving Up or Off the Sociological Agenda? *The Canadian Journal of Sociology,* 29(3), 459-467.

Pursglove, M. & Komarova, A. (2003). The Changing World of Russian Deaf Community. In L. Monaghan, C. Schmaling, K. Nakamura, & H. G. Turner (Eds.), *Many Ways to be Deaf:*

International Variation in Deaf Communities (pp. 249-260). Washington DC: Gallaudet University Press.

Rao, S. (2001). 'A little Inconvenience': Perspectives of Bengali Families of Children with Disabilities on Labelling and Inclusion. *Disability & Society,* 16(4), 531-548.

Rapp, R. (2000). *Testing Women, Testing the Festus: The Social Impact of Amniocentesis in America*. New York: Routledge.

Raz, A. & Amano, Y. & Timmermans, S. (2018). Parents like me: Biosociality and Lay Expertise in Self-Help Groups of Parents of Screen-positive Newborns. *New Genetics and Society*, 37(2), 97-116.

Rioux, H. M. (2002). Disability, Citizenship and Rights in a Changing World. In C. Barnes, L. Barton & M. Oliver (Eds.), *Disability Studies Today* (pp. 210-227). Cambridge: Polity Press.

Rogers, C. (2007). Disabling a Family? Emotional Dilemmas Experienced in Becoming a Parent of a Child with Learning Disabilities. *British Journal of Special Education,* 34(3), 136-143.

Rose, N. (2007). *The Politics of Life Itself: Bio-medicine, Power, and Subjectivity in the Twenty-First Century*. New Jersey: Princeton University Press.

Rose, N. & Novas, C. (2005). Biological Citizenship. In A. Ong and S. Collier (Eds.), *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*, (pp.439-463). MA: Blackwell.

Runswick-Cole, K. (2007). 'The Tribunal was the most stressful thing: More stressful than my son's diagnosis or behavior': The Experiences of Families who go to the Special Educational Needs and Disability Tribunal (SENDIST). *Disability & Society,* 22(3), 315-328.

Ryan, S. & Runswick-Cole, K. (2008). Repositioning Mothers: Mothers, Disabled Children and Disability Studies. *Disability & Society,* 23(3), 199-210.

Ryan, S. & Runswick-Cole, K. (2009). From Advocate to Activist? Mapping the Experiences of Mothers of Children on the Autism Spectrum. *Journal of Applied Research in Intellectual Disabilities,* 22(1), 43-53.

Sarı, H. (2005). An Analysis of the Relationship Between Identity Patterns of Turkish Deaf Adolescents and the Communication Modes Used in Special Residential Schools for the Hearing Impaired and Deaf. *Deafness and Education International*, 7(4), 206-222.

Scully, L. J. (2012). Deaf Identities in Disability Studies: With or Without Us? In A. Roulstone, C. Thomas and N. Watson (Eds.), *Routledge Handbook of Disability Studies,* (pp. 109-122). London: Routledge

Sengbas, J. R. (2003). New Ways to be Deaf in Nicaragua: Changes in Language, Personhood, and Community. In L. Monaghan, C. Schmaling, , K. Nakamura, & H. G. Turner (Eds.), *Many Ways to be Deaf: International Variation in Deaf Communities* (pp. 260-283). Washington DC: Gallaudet University Press.

Shakespeare, T. & Watson, N. (1997). Defending the Social Model. *Disability & Society,* 12(2), 293-300.

Shakespeare, T. & Watson, N. (2001). Disability, Human Rights, Law and Policy. In G. L. Albrecht, M. Bury & K. Seelman (Eds.), *The Handbook of Disability Studies* (pp.565-585). California: Sage Publications Inc.

Shakespeare, T. & Watson, N. (2002). The Social Model of Disability: An Outdated Ideology? *Research in Social Science and Disability,* 2, 9-28.

Shakespeare, T. (2006). *Disability Rights and Wrongs*. London: Routledge.

Siebers, T. (2006). Disability in Theory: From Social Constructionism to the New Realism of the Body. In L. Davis (Ed.), *The Disability Studies Reader Second Edition* (pp. 173-185). New York: Routledge.

Singh, I. (2004). Doing their Jobs: Mothering with Ritalin in a Culture of Mother-Blame. Social Science & Medicine, 59(6), 1193-1205.

Snell, L. (2015). Documenting the Lived Experiences of young adult Cochlear Implant Users: 'Feeling' Sound, Fluidity and Blurring Boundaries. *Disability & Society,* 30(3), 340-352.

Sparrow, R. (2005). Defending Deaf Culture: The Case of Cochlear Implants. *The Journal of Political Philosophy,* 13(2), 135-152.

Thomas, C. (2002). How is Disability Understood? An Examination of Sociological Approaches. *Disability & Society*, 19(6), 569-583.

Traustadottir, R. (1991). Mothers Who Care: Gender, Disability and Family Life. *Journal of Family Issues*, 12(2), 221-228.

TUIK (Turkish Statistical Institute). (2010). *Survey on Problems and Expectations of Disabled People*. Retrieved from:
https://biruni.tuik.gov.tr/yayin/views/visitorPages/index.zul.

Weiss, M. (1997). Territorial Isolation and Physical Deformity: Israeli Parents' Reaction to Disabled Children. *Disability & Society,* 12(2), 259-272.

Wiefferink, C.H., Vermeij B. A. & Uilenburg, N. (2012). Family Counseling in the Netherlands for Turkish-origin Parents of Deaf Children with a Cochlear Implant. *American Annals of the Deaf,* 156(5), 459-468.

Williams, G. (2001). Theorizing Disability. In G. L. Albrecht, M. Bury & K. Seelman (Eds.), *The Handbook of Disability Studies* (pp. 123-145). California: Sage Publications Inc.

Yazıcı, B. (2012). The Return to the Family: Welfare, State and Politics of the Family in Turkey. *Anthropological Quarterly*, 85(1), 103-140.

Yentürk, N. & Yılmaz, V. (2017). Türkiye'de Engellilere Yönelik Kamu Harcamalarının On Yıllık Seyri. *Çalışma ve Toplum*, 1, 59-74.

Yılmaz, V. (2010). *The Political Economy of Disability in Turkey's Welfare Regime*. (Master Thesis), Boğaziçi University.

Yılmaz, V. (2013). Changing Origins of Inequalities in Access to Healthcare Services in Turkey: From Occupational Status to Income. *New Perspectives on Turkey,* 48, 55-77.

Zeshan, U. (2002). Sign Language in Turkey: The Story of a Hidden Language. *Turkic Languages*, 6, 229-274.

Original Quotes

[1] Beşinci altıncı ayından sonra Barış'da bir değişiklikler olmaya başladı, net hatırlıyorum. Dedim ki bu çocukta bir şey var. Acaba sigara içtim, geç doğum yaptım diye sorgulamaya başladım. İlgisini çekebilir miyim diye televizyonun sesini açıyorum, kısıyorum, açıyorum, kısıyorum, tık yok. Hiç tepki yok Barış'da. Benim aklımda şey vardı o zaman, mutlaka bir sıkıntı var ama geçecek yani tedavi ile ya da ameliyat ile.

[2] Bir anda bize özgü hayatım yerle bir oldu.

[3] Eda iki aylıktan itibaren televizyon izlemeye çok meraklıydı. Onun için ben işitme problemi gibi bir şeyden hiç şüphelenmedim. Ama halası seslere tepki vermiyor deyince, ben de gözlemeye başladım. Televizyona sırtını döndürüp test ettim, tepki vermedi. Düşünüyorum kendi kendime, acaba var mı bir şey diye ama hala emin de olamıyorum. Ailede de ne benim ailemde ne de kocamın ailesinde işitme problemi gibi bir şey var.

[4] Penisilin iğnesi işitmesine zarar verdi. Ama tabi bunu fark etmek çok zor oldu. İğneden sonra Emir'in tepkilerinde bir durgunluk. Ben o zaman çalışıyordum, babam söyledi Emir'in duyamıyor olabileceğini. Aklıma geliyordu benim de, endişeleniyordum ama hiç ihtimal de vermiyordum. Çok zor yani bu kadar sevdiğinde böyle bir şeyi kabul etmek.

[5] Doğum öncesi işitme testi o zamanlar zorunlu olmadığı için, bir işitme kaybı olup olmadığını bilmiyoruz, Defne'nin doğumunda. O sıralar sadece riskli hamileliklerde yapılıyor. İşte ikiz bekliyorsan ya da ailende akraba evliliği varsa. Böyle bir testin olduğunu bile bilmiyorum yani ben. Defne bir yaşındayken konuşmaya başladı, ben de yavaş yavaş artık işe dönmeyi planlıyorum. Sonra ama çok ağır bir grip geçirdi ve bir ay gibi sürdü, çok zor iyileşti. Çamaşır makinesi çalışırken de uyumaya başladı, sesten uyuyamazdı. Ben de bir şey olabileceğini düşünüyorum ama annem de çok tepki veriyorsun filan diyor. Yine de ikna olmadım, aldım doktora götürdüm. Doktor da endişelenecek bir şey yok dedi. En sonunda, alıp üniversite hastanesine götürdüm. Orada hani sırf benim kuruntularım bitsin diye bir test yapabileceklerini söylediler.

[6] Ben sonradan fark ettim. Önce fark eden babamız. Bana da sonradan söylüyor, meğer Elif'in yatağına gidiyormuş kontrole, duyuyor mu diye yatağını sallıyormuş, ses yapıyormuş. Ben bizim aile doktorumuzu aradım böyle bir şey olabilir mi diye. Güldü bana. Dedi ki "sen 19 sene bekledikten sonra kusur bulmak istiyorsun herhalde. Yok bir şey." Biz evliliğimiz boyunca, çocuğumuz olsun istedik. Elif 19 yıl sonra geldi bize. Havalara uçtuk. Yani benim için çok zordu benim yavrumun diğerleri gibi olmadığını kavramak. Hala da pişmanımdır ilk ben fark etmedim diye. Ya da kendimi kandırıyordum belki de bilmiyorum.

[7] Çocuğumun sağır olacak diye çok korktum. Eşimin kardeşinin oğlan sağırdı ve çocuk mahvoldu. Kimse ilgilenmedi, iyicene bir değişik oldu, sokaklarda gezmeye başladı gece gündüz. Sokaklarda çok da çektirdiler çocuğa. Her verdikleri şeyi alıyordu. Önce çok sağlıklı bir kızım oldu. Sonra oğlum doğdu. Çocuğun beni görmeyince tepki vermediğini fark ettim birkaç ay sonra. Yani beni takip edebiliyor ama ben görüş alanından çıkarsam ağlamaya başlıyor. Kaynanama, kayınbabama da hiçbir şey söylemedim ilk başlarda. Çünkü o çocuğun başına neler geldiğini de biliyordum. Zaman geçtikte herkes farkına vardı tabi.

[8] Biz düzenli olarak hastaneye gidiyoruz Bera testine randevu alalım diye. Oraya test için gittiğimizde ilk, makine bozuk dediler, yapamadılar. Sonra işte bir işitme merkezinde randevu aldık. Defne'nin işitme kaybı 100 desibel çıktı. Doktor bana örneklerle açıkladı yani uçak kalksa fark etmez filan dedi. Ben neye uğradığımı şaşırdım o saniye. Eşimle çok güzel bir aşkımız vardı, para kazanıyorduk, işimiz gücümüz yerindeydi. O an her şey anlamını yitirdi çünkü hayatım sona erdi gibi oldu.

[9] Bana kızın sağır dediklerinde ben bayılmışım. Böyle ellerimden kaydı gidiyor hayatım gibi düşündüm. Çok ağladım ama kızıma da bir hayat sunmam gerek. Önüme bakmam lazım. Derhal durmaksızın kızımla ilgileneyim diye işi bıraktım.

[10] Çok tasalanıyordum çünkü eşimin ailesi kendi haline bırakın bu çocuğu diye çok baskı yaptı. Benim kocam da o zaman onlardan çabuk etkileniyordu, hemen bana söyleniyordu boşu boşuna uğraşıyorsun diye. Benim o sırada kaybedecek hiçbir şeyim yok, kocama da dedim hemen boşanırım, çocukları da alır çeker giderim diye. Tehdit olsun diye de söylemedim, hala onlar gibi düşünseydi yapardım da. Erzurum'da kocam lazım çünkü sen de biliyorsun, orası ufak yer, boşanan kadına kötü gözle bakılır. Ama büyük şehirlerde öyle değil, ben de çocuklarıma bakacak bir yol bulurum tek başıma diye düşündüm.

[11] BERA testini yaptırdıktan sonra bize hastaneden resmi rapor almanıza gerek yok dendi. Test sonuçlarına göre de hemen ayarlarını yaptılar Defne'nin cihazının. Bir ay içinde biz tekrar doktora taşındık, doktor hanım bir baktı ki cihaz tamamen yanlış ayarlanmış. Bu sefer yeni bir tane cihaza ihtiyacımız oldu. Hemen merkezi aradım iade etmek için ama iadeyi kabul etmediler. Neyse sonradan anlaşılıyor ki, bizim cihazı alırken imzaladığımız kontrata göre böyl bir şart yok zaten. Bu sefer tekrar doktor hanıma gittim ki bize bir rapor yazsın, biz de işitme merkezine götürelim ve bir kanıtımız olsun hani elimizde. Doktor rapor yerine, sürekli başka bir marka cihaz öneriyor. Yani aynı ilaç sektörü gibi, işitme cihazı şirketleri de doktorlara komisyon veriyor.

[12] İyice geciktik diye ben artık Erzurum'daki doktorlara İstanbul'da kime görünülür diye sormaya başladım. Öyle geldik Kadıköy'e hastaneye. Orada dediler ki bu çocuk işitme cihazı takacak. Ücret de 1000 lira. Tamam, iyi diyorsun da ben nasıl alayım bunu? Nerelere gittim, hastanelere, belediyelere ama yok hiç umut yok. Bir sene daha geçti, sonra bir doktor bizi belediyeye gönderdi. Belediye yarısını karşıladı, 1000-1000 gibi. Oğuz takı cihazı ama ilk akşamında ateşlendi. Tekrar o doktoru bulamadım sonradan ama başka bir doktor muayene etti ve bu cihaz çocuğun kulağına uygun değil dedi. Çok acılar çekti benim oğlum, zaten bir daha da takmadı.

[12] Defne yaramaz bir çocuktu, yatıştırması kolay bir çocuk değildi. Bize işte öğretiyorlar, gökyüzü, mavi, ağaç, toprak, işte uçak filan. Ben de işte sürekli Defne'yi parka götürüyorum ki, bak işte bu gökyüzü, bak işte ağaçlar falan diye anlata anlata göstereyim ona. Ama yine de hiç kelimelere ilgi gösteren bir çocuk değil. Hala da değil. Öğretmenler, beni çocuğumu iyi tanımamakla suçladı. Neymiş, ben bu çocuğu evde çalıştırmalıymışım, yoksa dikkati dağılırmış. Bunu da denedim, bir hafta evden adım atmadık, bir gelişme göstermedi. Yani bu uzmanların dediği gelişmeyi bir türlü göremiyorsunuz. Çok sıkıntılı bir süreçti, Defne kelimeleri söyleyemedikçe ben daha da agresifleşiyordum.

[13] Rehabilitasyon da efendim kedi miyav miyav, köpek havhav diye geçiyor. Yani çocuğum hiçbir şey öğrenmedi orada. Ben ne yaptım onun yerine? Mesela, rehabilitasyondan

gelirdik, stickerlar var, ben her yere stickerlar yapıştırırdım ki bana ne yediğini işaret etsin. Fasulye mi yedi? Nohut mu? Ya da işte bütün mobilyalara sticker yapıştırdım ki kelime öğrenebilsin, kelime yapabilsin. Böyle böyle implant olamamış bir çocuğun özel eğitim açığını kendime göre kapamaya çalıştım. Çok şeyler başardım. Ne rehabilitasyon ne okul, çocuğuma her şeyi ben öğrettim.

[14] Yaşadıklarımızdan sonra doktorlara güvenemiyordum, hiçbiri uzman gibi gelmiyordu. Bir arkadaşım bana Ankara'da üniversite hastanesini önerdi. Bana da ulaşım filan çok zor olur gibi geldi ama bir yandan da İstanbul'da güvenebileceğim bir doktor yok yani. İstanbul'da vizitesi 300 lira olan bir odyoloğa gidiyorduk iki haftada bir. Bir gün telefonla bir şey danışmam gerekti, beni tanımadı adam. Sonra Ankara'ya e-mail attım ve çok nazik bir cevap aldım. Kayınvalidem ile gittik, bütün doktorlar baya dikkatli muayene ettiler Defne'yi, ilk defa pedagojik davrandılar çocuğa. Ben de ilk defa böyle rahatlamış hissettim tanıdan sonra. Defne'yi hepsi Koklear İmplant için uygun buldu. O yaz için Defne'yi ameliyata almaya karar verdiler ve çok başarılı bir ameliyat geçirdik. Ben de Koklear İmplant'ı biliyorum tabi çok duydum ve umduğum şey de o ameliyattı aslında.

[15] İki ay sonra özel eğitime geri döndük. Defne kelimeleri öğrenmeye başladı ve çok hafif desibeldeki sesleri de duymaya başladı. Bir ben anlayabiliyordum ne dediğini, başka kimse anlamıyordu. Ben de hiç normal bulmuyordum bunu, yine bir terslik var diye düşünüyordum, rehabilitasyondaki öğretmen yine beni suçluyordu evde alıştırmaları yapmıyorum diye. Kadın inanmıyordu zaten bana, alıştırmaları yaptığını göreceğim, kameraya kaydet getir filan diyordu. Ona göre problem benim Defneyle ödev yaparken doğal davranmamam. Bu yüzden konuşmuyormuş. Neyse, bunlarla ilgili değilmiş tabi Defne'nin fonolojik konuşma bozukluğu diye bir şey olduğunu öğrendik, tabi öğretmen bunları değil benden şüphe etmeyi düşünüyor bir tek.

[16] Elif'e işaret dili yasaktı. Bizim bir sürü çocuğumuz implantlanmış olmalarına rağmen konuşmuyorlar. Elif geçen sene iyice işaret diline merak saldı. Ben de çocukta bir gerileme gözlemledim. Ama bunu kabul edemem ben. Yani bu çocuk konuşmalı, bu toplumda yaşayabilmeli. Çünkü biz ona öğrettik aslında akıcı konuşmayı. Çoğu insan sağır olduğunu bile anlamıyor. Yani sadece, anlamada bir güçlük çektiğini düşünüyorlar çünkü kelime dağarcığı çok zayıf.

[17] Bizim sağlık sistemimizde yanlış bir yönlendirme var. Doktorlar çocuğa işitme kaybı tanısı koyduğunda sanki Koklear İmplanttan başka o çocuğun bir alternatifi yokmuş gibi yaklaşıyorlar. Mesela, öyle vakalar oluyor ki, anne-baba ya da biri sağır olunca hemen ebeveynlere çocuğun Koklear İmplant ameliyatı olması gerektiğini söylüyorlar ve çocuklarıyla işaret dili yapmasını yasaklıyorlar. Ne anlama geliyor bu? Sen ailenin çocukla bir ilişkisi olmasını engelliyorsun. Bu ailelerin kabul edebileceği bir şey değil. Peki duyan ailelerde ne oluyor? Sen öyle bir başlıyorsun ki konuşmaya sanki çocuk ameliyat olmazsa bir hayatı olamazmış gibi. Yani ne oluyor? Bir sakatlaştırma süreci başlıyor. Hem çocuk için hem de aile için. Çok savunmasız hissediyor aileler kendini, ne yapacaklarını bilemiyor. Sen aile ve çocuk arasındaki ilişkiyi sakatlamış oluyorsun. Herkes implant takılınca sağırlık bitti gibi düşünüyor. Çocuk konuşur konuşmaz, işte koklear implantın başarısı gibi görülüyor. Halbuki, hiç değil. Hem tıp dünyası hem de rehabilitasyon olarak bütün anlayışımız yanlış. Biz bu çocuklarda konuşmayı değil, anlamayı hedeflemeliyiz. Konuşma ardından adım adım gelir.

[18] Türkçe, matematik, fen gibi dersleri konuşarak ve tahtaya yazarak anlatmak tabi çok bir şey vermiyor çocuklara, anlamıyorlar, okuma, yazma becerileri gelişmiyor. Yani lise düzeyindeki çocuklar daha anca adreslerini yazabiliyorlar. Ne oluyor tabi sonuç olarak, sağırlık zaman içerisinde zihinsel engelmiş gibi algılanıyor.

[19] Rehabilitasyon işitme engelli çocuklar için bir yuvaya yazdırmamı önerdi. Ama ben de istiyorum ki evladım topluma ayak uydurabilsin, sesin çok olduğu ortamlara aşina olsun ve yaşıtlarıyla olsun. Ben 18 tane yuva gezdim. İçlerinden sadece bir tanesi dedi ki biz çocuğunuzu alacağız ama bir aylık deneme ile. Fakat dedi, arkadaşlarının ona uyumu bunu belirleyecek dedi. Çocuklar kabul ederse kalabilir. Çok şükür, bir sorun yaşamadık, ilköğretime kadar orada kalmayı başardık.

[20] Bu çocuklar hayatlarını sadece işitme engelli okullarında geçiremezler. Onların da toplum içinde olması lazım, onların da bu toplum nasıl işliyor öğrenmeleri lazım.

[21] Biz rehabilitasyondan 12 anne, çok az vaktimiz var ve çocukları kaydettirecek bir okul arıyoruz. İstanbul İl Milli Eğitim Müdürlüğünden randevu aldık. Başlangıçta randevu alamadık, çok yoğun olduğundan ama sonra halk günü oluyormuş vatandaşların taleplerini, şikayetlerini dinledikleri, biz de pes etmedik, oraya gittik. Beni bizim grup sözcü olarak seçti, ben de dedim ki bize bir okul ve sınıf göstermeniz lazım çünkü bu çocuklarımızın düzgün eğitim alması şart. Sadece bir sınıf göstermesini istedim. Sınıfa bir bağış bulacağımın da sözünü verdim. Benim sözümü kesti, buna elverişli ne finansal ne de eğitim hazırlıkları olmadığını söyledi. Biz de teşekkür ettik, çıktık. Ama bir cevap alalım istiyoruz, bu sefer valiye gittik. O daha sıcak karşıladı bizi ve bir toplantı sözü verdi, hem de o yetkili de katılacak. Orada da dedim yani "siz bizden ne yapmamızı bekliyorsunuz? Ne yapalım bu çocukları toptan yok mu edelim?" Adamın yüzünün rengi değişti ve valinin önünde bize bir yer bulacağının sözünü verdi. Bir hafta sonra Aksaray'da bir devlet okulunda bir sınıf bulduklarını söylediler. Ben okulu ziyaret ettim, okulun böyle bir şeyden haberi yok. Sonra tekrar geri gittim ki süreci takip ettiğim anlaşılsın. Okulun başlamasına bir hafta kala, bize Aksaray'da bir sınıf açtılar ve ben de özel eğitim için bağış yapmak isteyen birini buldum. Bu şekilde başladık örgün eğitime.

[22] Eda orada okumayı yazmayı öğrendi, dudak okumada ustalaştı.

[23] Sevincim kursağımda kaldı. Kocama falan da söylemiştim çalışacağımı, kabul etmişti o da. Her zaman çocuğun yanında olabileceğim okul zamanı. Bir hafta sonra müdür bey aradı tekrar. Bana okulda hizmetli olarak çalışmayı kabul edersem çalışmaya başlayabileceğimi söyledi. Bir hizmetli arıyorlarmış ve bütçeleri de yokmuş. Çok gücüme gitti. Temizlik yapmaktan utanacağımdan değil de müdür bana nasıl böyle emrivaki yapabilir diye. Kabul etmekten başka bir çarem de yok. Hem serviste hostes hem de okulda hizmetli olarak çalışmaya başladım, sadece oğlum okula gidebilsin diye.

[24] Öğretmenlerin biri geliyor, biri gidiyor ama hiçbir gelişme yok eğitim anlamında. Kaç kere de şikayette bulundum öğretmenler hakkında anlatamam.

[25] O sınıf iki sene sürebildi. Her şey problem oldu. İlk seneden kısa bir süre sonra, vali istifa etti ve yeni atanan vali pek ilgilenmedi. Sınıfa bulduğumuz öğretmen kütüphaneciydi ve bizim çocuklar diğer akranları gibi öğrenim göremediler ilk yıl. Orada iki yıl kalmayı başardık ama hep kendi kişisel çabalarımızla. Sonra ama İstanbul'da bir işitme engelli okuluna yerleştirildik.

[26] Tamam, akranlarıyla yuvaya gitsin diye çok bastırdım ama ilköğretim başlı başına başka bir şey. Matematik, Türkçe filan nasıl öğreteceğim? Bir işitme engelli okuluna baktık, servis de yok ulaşım için. Taksi ayarladık ve çocuk eğitime başlayabildi. Ben kendim çaba da sarf ediyorum eğitim için ama evladım, A'dan B'ye geçemiyor. İşaret dili yasak. Çocukların ellerine vurduklarına işaret yapmasınlar diye ben şahidim. Öğretmen dersi anlatıyor, yazıyor tahtaya sonra da bağıra bağıra kendini duyurmaya çalışıyor. Bu şekilde bu çocuklar öğrenebilir mi bir şey?

[27] Hep öğretmenlerle kontaktayım. Sadece çok basit seviye şeyleri öğrenebildi, bu çabama rağmen dersleri anlasın diye. Bugün bile gazete okuyamaz. Dakikasında sıkılır, tam anlayamaz. Ama öğretmenlerin çoğu ilgisiz. Örnek vereyim, işaret dili yasak, ama işaret dilinin eksikliğini dil becerisi vererek de kapamıyorlar. Çocuk bir şey öğrenemiyor diye gittiğimde bana mutlu olun, en azından okuma yazması var dedi.

[28] Daha da içe kapanmaya sebep oluyor.

[29] Benim çocuğum işaret dilini sınıf arkadaşlarından ya da daha üst sınıflardaki abi ablalarından teneffüste gördükleriyle öğrendi. Ailelerinde sağır olan çocuklar diğerlerine işaret yapmayı öğretiyor. Bu resmen kural gibi bir şey. Oğlum da çok hızlı öğrendi işaret dilini. Neden? Çünkü o onun doğalı. Öğretmenler de uyardı beni, işaret dili kullanırsa bir şey öğrenemez diye. Bu beni çocuğum TİD kullanıyor diye hep huzursuz etti.

[30] Biz o devlet okulunda özel sınıftayken işaret dili hakkında hiçbir fikri yoktu. İşaret dilini sağır okuluna gidince yapmaya başladı, çok çabuk öğrendi. Öğretmenlerin işaret dili bilmediğini de biliyordum ve nasıl öğrendiğini de çok merak ediyordum. Ailesinde sağır olan arkadaşlarının dili öğrettiğini söyledi.

[31] Benim kızım hep geriledi işitme engelliler okulunda. Kazandığımız her zaferi de kaybetmiş olduk, rehabilitasyon ve özel eğitim aracılığıyla. Birkaç ayda öğrendi işaret dilini ve sonra konuşma egzersizlerinin üstüne çok düşmemeye başladı.

[32] Eda için "k" harfini çıkarmak çok zordu. Harfi çıkaramıyordu. Böyle dilinin arkasıyla gırtlağına bastırması lazım ama duymadan zor bu harfi çıkarmak. Ben bu uzun bir süreç, kesin çıkaracak diye bakıyorum. Ama işaret dili öğrenmeye başladıkça, ben de onu kaybetme korkusu başladı. "K" sesi yaparken titreşimi hissetsin diye, çubukla ittirirdim dilini damağına doğru. İşaret dili duraksattı, sebep oldu diye düşündüm. Ellerini de arkada birleştirtirdim ki dudak okumaya, konuşmaya çalışsın eskisi gibi. Şimdi bu korkunun bana neler yaptırdığını görünce, çok kötü şeyler yapmışım diyorum. Onun yaşam hakkını elinden almışım, istediği gibi olmasına izin vermemişim.

[33] Ödevini yaptırırken, ona asıl öğrenmesi gerekenleri de göstereyim diye gayret ediyorum. O yüzden herhalde işaret dili bana hep okuldaki vasatlığı kabul etmek gibi geldi. Her şeyi yaptım konuşabilsin, sesleri ayırt edebilsin diye. Evdeki her eşyanın üstüne, her metrekareye stickerlar yapıştırdım. Tüm mahalleyi tembihledim, o bir şey almaya ya da karnını doyurmaya gelirse onunla konuşsun diye. Otobüsteyken şoförle o irtibata geçsin diye çok ısrar ettim, manava gitsin diye. Bunları normal bir çocuk olsun diye yapmam gerekiyordu.

[34] 1993'te ateşli hastalık geçirdim ve işitmemi kaybettim. Annem babam çok araştırma yaptı tedavi için. Yani Türkiye'de doktorlar aileme bu çocuk sadece işitme

engelliler okuluna gidebilir ve işaret dili ile anlaşabilir demişler. Ailem de hiçbir çare bulamazlarsa bunu yaparız diye düşünmüşler. Annem de hostes benim, çok sehayat ediyordu ve implant araştırmaya başladı. Önce güney Afrika'da buldular ama ameliyat için vatandaş olmak gerekiyormuş. Sonra bizi Almanya'da odyologlarla iletişime geçirmişler, onlar da Türk odyologların Koklear İmplant teknolojisini öğrenmeleri için bana Türkiye'de örnek bir ameliyat yapmayı teklif etmişler. Türkiye'de ilk koklear implant kullanıcısı benim o yüzden, hiçbir devlet desteği ve sigortası olmadan. Annemin arkadaşları ameliyat parasını aralarında toplamışlar. Doktorlar da sadece ameliyat masraflarını almışlar, koklar implant için bir şey almamışlar. İlk olduğum için, hediye ettiler.

[35] Melis'e imreniyorum. Evet, itiraf edeyim Edayla bir çok zorluğun üstesinden geldik ama hayatı çok daha başka olabilirdi. Üniversiteye gidebilseydi çok daha düzgün bir şte çalışabilirdi.

[36] Herkes Koklear Implantlılar kadar şanslı olamıyor.

[37] Kafasında antenle dolaşmak istemediğini söylüyor.

[38] İşitme engelli çocukların aileleriyle tek bir gün geçirseniz, hastanelerde veya okullarda, devletin işitme engelli vatandaşları göz ardı ettiğini anlarsınız. Ama söz konusu benim oğlum, ben onu sisteme kurban edemem. Hep söyleriz, bizim engelli aileleri olarak şansımız yok diye. Ama dernek fikri işte bize birbirimizin bir şansı olsun, kendi şansımız olalım diye bir yol açtı.

[39] Çevremde bilgili kimse yok. Beni yönlendirebilecek bir uzman olur diye düşündüm ama rehabilitasyon merkezinde kimseyi bulamadım. O zamanlar ben de çok fevriydim, çünkü evladımın tek destekçisi benim. Okuldaki öğretmen ve idarecilerin korkulu rüyası oldum. Çünkü bizler hastane kapılarında, rehabilitasyon merkezlerinde, okul bahçelerinde hep ağlardık. Sinirimiz hep bozuk. Barış'ın okulunda idealist bir öğretmen vardı, ondan duydum böyle bir dernek olduğunu. Düşündüm taşındım bari enerjimi iyi bir amaç için harcayayım dedim. Hep kendi kendime derdim ki, sağırlık yeni bir şey değil, yüzyıllardır var. Devlet buna benden daha aşina, benden daha iyi biliyor. Beni yönlendirebilirdi, olmadı. Biz kendi başımızın çaresine baktık.

[40] 2010 yılında işitme cihazı ile ilgili birtakım sorunlarımız vardı, internette Googlelarken buldum derneği. Arayınca Gönül ile tanıştım. O kadar yardımcı geldi ki, o bunların hepsini yaşamış. Önce sakinleştirdi beni tanışıyormuşuz gibi sonra da derneğe davet etti tanışalım diye. Benimle benzer badireler geçirmiş kimseyi tanımıyordum. Ama öğrendim. Meğer benimkine kıyasla aileler ne kadar daha zor güçlüklerle mücadele ediyormuş.

[41] Leyla'yla okuldan tanışıyoruz, hep de iletişimdeydik oradaki sorunlar ile ilgili. Böyle böyle seni Sandra diye biriyle tanıştırayım deyince nasıl mutlu oldum. Biz çok şeyler kaybettik teknolojiye erişemediğimiz için ama belki daha gençler için bir şeyler yapabiliriz dedik. Çok yalnız geçirdik biz, hep bir tek bizim başımızda bu acılar var diye düşündük. Ama annelerle tanışınca, hep benzer tecrübeler duyunca, yalnız olmadığımı öğrenmiş oldum.

[42] Biz de biliyoruz bu ana okul ya da yasal bir şey için bastırmak gibi bir şey değil. Ama birinin bile bir şeye ihtiyacı varsa, derhal onu ihtiyacına yetişmeye çalışıyoruz. Kendi çocuklarımızın eski cihazlarını bile verdiğimiz oluyor bizden daha ihtiyaçlı aileler olunca.

[43] Ben havalara uçuyorum bir merkez buldum diye. İlk başta dediler ki eşinizle beraber katılmanız gerekiyor derslere. Ben de hayhay dedim, gittim. Eve dönerken, eşim dedi ki haberin olsun ben her derse katılamam. Masraflar da boşuna dedi, dedi nasıl olsa Eda düzelmeyecek. O zaman anladım işte ben mücadelemde yalnızım. Hep bahaneler uydururdum, bazen onu iş seyahatine yollardım, bazen hasta yapardım. Kim beni nasıl anlasın? Sadece dernekteki anneler anlar. Bazen Gönülle uzun terapiler yapıyoruz, yalnızlığımızdan dem vuruyoruz. Hep dertler aynı.

[44] Biz bilmeyiz komşularla günlere gidelim. Kocalarımız misafir çağıracak diye ödümüz patlıyor. Bu işlerde hep kadük kaldık. Ama işitme engeli konusunda uzman olduk, hangi hastaneye gidilir, itiraz edilecek raporlar, biz böyle birbirimizin problemlerini biliyoruz. Ondan birbirimizin hayatını kolaylaştırıyoruz.

[45] Ben hep kendimi sorguluyordum. Kimim? Anne miyim? Öğretmen miyim? Sürekli anneliğimi sorguluyordum. Etrafımdaki herkes, arkadaşlarım, akrabalarım bana acıyormuş gibi geldiler hep. Kendi kendimi yalnızlığa sürükledim. Evliliğim de etkilendi. Kocamla da boşanmaya karar verdim. Çünkü bu saatten sonra bana bir yararı yok, iyiliği dokunmaz diye düşündüm. Ben istifa etmişim, o kendini işe adamış Defne'nin ihtiyaçlarına yeteceğim diye. Aile kurmak, evlilik, çoluk çocuk bunlar hep zor şeyler biliyorum ama bir engelli annesi olmak çok başka bir şey. Gönül'e de anlattım bunlar beni mahvediyor, çok zorlanıyorum diye. O da dedi ki kimseyi takma, kimseyi dinleme.

[46] Biz aktivite organize ettikçe, yavaş yavaş insanlar, aileler bizden haberdar olmaya başladı. Çocuklar sosyalleşsin diye bir piknik ayarladık. Ama hiçbir işe yaramadı. Koklear İmplantlılar bir yerde, cihazlılar bir yerde, sağırlar başka bir yerde kendi aralarında. Haa, bu hepimize ders oldu. İki şeyde karar kıldık. İşaret dilini gündemimize alalım. Çoğumuz işaret diline karşıydık, hala da karşı olanlarımız var açıkçası. Ama bunu çocuklarımız varlık göstersin diye yapmamız gerekti. İkincisi, çocuklarımızın arasındaki eşitsizlikleri ortadan kaldırmak için bir gündem yapalım dedik. Hak temelli bir duruşumuz olsun diye karar verdik. Daha o zaman engelli hakları nedir ne değildir, pek haberimiz yok ama biliyoruz, hissediyoruz neyin adaletsiz olduğunu.

[47] Implantlılar da dahil diğer üyelerle konuştum, işaret dili dersleri açacağımızı bildirdim. Çünkü bu sırada sağırlar da derneği öğrenmeye başladı, raporlar hakkında, emeklilik hakkında danışmaya geliyorlar. Ben işaret dilini ciddiye almayan annelere bir şey diyemem çünkü onlar çocuklarıyla dudak okuyarak iletişiyorlar. Ama bazen koklear implantlılara çok öfkeleniyorum. Hep diyorum onlara, siz sağırlarla eşitsiniz diye. Cihazı çıkarınca hepsi bir. Ama üstünlük taslıyorlar sağır çocuklara.

[48] Çoğumuzun çocuğu eğitim hakkından mahrum kaldı. Milli Eğitim'in dağıttığı okul kitapları mesela normal okullarla aynı. Nasıl anlasın bizim çocuklar bu kadar az eğitimle böyle uzun, karmaşık paragrafları? Karışık cümleleri açıklamak bize kalıyor sonra. Mesela, yol açmak deyimi. Bizim çocuklar bunu gerçek sanıyor. Gerçekten biri yolu kazıyor sanıyor. Dilekçeler yazdık ilgili bakanlıklara, okul yönetimleriyle paylaştık. En sonunda, işitme engelli okulları için kitaplar yeniden düzenlendi, bir sonuç almış olduk.

[49] 2005'deki Özürlüler Kanunu'nu biliyorduk. Ama zannetme ki biz resmi derneğiz diye bize bir yazı geldi, medyadan, katıldığımız panellerden öğrendik. Sonra biraz araştırdık bu kanun bizim sorunlarımıza cevap mı diye. Olamadı, maalesef. Mesela, anneler işitme

problemini anca fark ediyor çocuklar neredeyse 6 aylık olduğunda. Diğer bir şikayetimiz yetersiz rehabilitasyon hizmeti ve okullar. Ya da tanılar da çoğunlukla yanlış ya da geç kalıyor. Bizim 3E sloganımız böyle çıktı. Biz diyoruz ki Erken Tanı, Erken Eğitim, Erken Cihazlanma. Çünkü biz bir jenerasyonu kaybettik, bir tane daha kaybetmek istemiyoruz.

[50] Biz çok geç öğrendik çocuklarımızın işitme engelini. Anca ilgisizliklerinden ya da ateşli hastalıklardan. Sonra dedik ki zorunlu hepatit taraması var yeni doğanlar için, neden işitme taraması olmasın. Ankara'daki bakanlıkları ziyaret ettik birçok kez, bakanlıklara ve kamu kuruluşlarına tonla dilekçe yolladık.

[51] Rehabilitasyon merkezleri bireysel dersler için ayda yalnızca 8 saat, grup derslerine de 4 saat ayırıyor. Implantlılara, cihazlılara bu süre çok yetersiz. Çocuklarımızın duyan çocuklara oranla daha çok görsel materyale ihtiyacı var bu yüzden aslında rehabilitasyon çok hayati çocukları karma veya işitme engelliler okuluna hazırlamada.

[52] Biz çocukları verebileceğimiz bir yuva, anaokulu istedik. Bazılarımız karma okulları da tercih edebildi ama bizim şansımız yaver gitmedi. İşitme engelli çocuğu kabul edecek okul bulmak çok zor. Biz de araştırmamızı yaptık, bir ana okul kuralım istedik, anneleri de tembihledik haberi yaysınlar diye. Üniversitelerle görüşmelerimiz oldu, işitme engelli çocuklara eğitim alanında uzman olabilecek kişiler bulmak için, belediyeler ile görüşmelerimiz oldu. Nihayet, bir belediyeyi ikna ettik, o belediyede bir devlet anaokulu vardı, orayı düzenleyecekler. Üniversitelerin sosyal kulüpleriyle bir araya geldik, bizim için para toplamak istediler. Bu parayı biz okulun ses izolasyonu ve görsel materyalleri için kullandık. Elimizden ne geliyorsa en iyisini yaptım ama bürokratlar değişince gidişat tökezledi. Çok uzun ömürlü olmadı. Ama en azından bu tecrübeyle biz okullarla, resmi makamlarla nasıl iletişim kurarız onu öğrendik.

[53] Ben muhasebeci olduğum için resmi yazışma usulünü, resmi makamlarla konuşmayı filan iyi biliyorum. Ama, burada çok şey öğrendim üzerine. Hangi kurula hangi bakanlığa ne dilekçe gönderilir, bunlarda hiçbir fikrim yoktu. Mesela, uzun zaman biz doğru birimi bulup öyle dilekçe yollamaya çalıştık. Ama bunu yapınca, herkes birbirine yönlendiriyor ve senin beklemen bitmiyor. Dersimizi aldık, 16 bakanlığa birden göndermeyi öğrendik.

[54] Çok resmi bir dille yazarsan, ciddiye alınmıyorsun. Çünkü oradaki gerçek tecrübeler kayboluyor, etkisini kaybediyor. Biz kendi tecrübelerimizi kendi kelimelerimizle kendi eleştirimizle yazmayı öğrendik. Bir düzen de oturttuk. Önce yürürlükteki yönetmelikleri yazıyoruz, sonra yaşadıklarımızdan yola çıkarak o yönetmeliklerin nereleri aksıyor, yetersiz ona değiniyoruz işliyor artık. Çünkü biz daha iyi biliyoruz, yaşadıklarımızı yazmak zorundayız. Yalakalık yapmıyoruz, kısa yazmıyoruz. Uzun ve samimi dilekçeler yazıyoruz. Bir keresinde, uzun bir dilekçe döşendim eğitimde noksanlıklar hakkında. Bir yetkili Ankara'dan, Özel Eğitim Müdürlüğünden saat akşam 7'de aradı beni ve vaktim olursa beni dinlemek istediğini söyledi. 45 dakika neredeyse sadece ben konuştum, kendisine çözüm bulamadığımız sorunlarımızı izah ettim.

[55] İşitme engelli çocuklara ek süre tanınmadığını biliyorum. Ek süre sadece görme ve fiziksel engellilere var. Bizim sorunlarımız daha çok insana ulaşsın diye basını davet ettim sınava ve duyma engellilerin bu haktan yararlanamadığını anlattım. Haftasonu girdi aray sonra devlet kurumlarına bir dilekçe yazdım ve haberi de ek kanıt olarak sundum. Ankara'dan

davet edildik bunun üstüne. Orada konuştuğumuz yetkili bize ek sürenin bir şey değiştirmeyeceğini söyledi, siz murat 124'le Mercedes'i kıyaslıyorsunuz dedi. Ben de biliyorum daha geniş çaplı değişikliklere ihtiyacımız var, görsel soru bankası, işaret dili tercümanı. Ama öyle sinir oldum ki cevabına, bu cevabı hemen birkaç köşe yazarına gönderdim. Biri bu arsız cümlesini teşhir etti ve o yetkili başka bir pozisyona geçirildi. Sorunumuzu çözemedik ama yine de işe yaramayan bir yetkiliyi görevinden almış olduk.

[56] Önce yaşadıklarımızı derneğin üyeleriyle paylaşıyoruz. Yeni gelenlere diyoruz ki sakın devlet kurumlarıyla ya da doktorlarla konuşurken yaşadıklarınızı anlatmaktan çekinmeyin. Onlara anlatıyoruz, bu kurumlar bize hizmet için varlar, bizi korkutmak için değil. Her gördükleri adaletsizliği yazmalarını söylüyoruz, takipçi olmalarını söylüyoruz. Biz de sıfırdan başlayıp sürekli resmi gazete takip edecek seviyeye geldik, onu anlatıyoruz.

[57] Dernekteki annelere katılmadan önce de biliyordum daha iyi tedavi daha iyi sosyal imkanlar istemek benim hakkım. Ama bu hakları ben nasıl dile getiririm onu bilmiyordum. Zaten Defne'nin ufacık yararlanabildiği haklar var, onlara bir zarar veririm eğer konuşursam diye düşünüyordum. Şimdi artık dile getirebiliyorum kendimi. Hiç kaba olmadan, ama çekinmeden.