

THE CONSTRUCTION OF DISABLED AS NEEDY AND INVISIBLE THROUGH
HELP-ONLY APPROACH: THE CASE OF VISUALLY DISABLED LIVING
IN ANKARA, TURKEY

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ABSTRACT

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The activities on disability issues are largely inefficient and ineffective. The common feature of this situation, which manifests itself in related practices, from disabled people and their families to the state administrators, is that people who turn theory into practice are members of the same society. Therefore, the fundamental social and cultural perception and understanding on disability put into practice by people who compose the society is one of the reasons of this situation.

This study is based on an eight-month ethnographic research conducted with visually disabled young persons living in Ankara. In order to reach the social and cultural approaches of the society towards the disabled, the common causes of issues emphasized in the fields of disability, family, education, workplaces, society and the state were analyzed in the light of the decisive factors for the participants.

As the conclusion, social and cultural reasons of the inefficiency and ineffectiveness are help-only approach, needy disabled assumption and invisibility of the disabled. According to help-only approach, a proposed conceptualization of the study, the only thing that can be done about the disabled is to help them. Since the approach leaves no room for a permanent solutions, it builds disabled people as needy and invisible. Also, with the dynamics of social life, just like a vicious circle, the invisibility of disabled people as a lack of awareness framed by misinformation and misconceptions reproduces the help-only approach.

Keywords: Disabled people, help, invisibility, inefficient implementations, daily life

ÖZ

SADECE-YARDIM YAKLAŞIMIYLA ENGELLİLERİN MUHTAÇ VE GÖRÜNMEZ OLARAK İNŞASI: ANKARA'DA YAŞAYAN GÖRME ENGELLİLER ÖRNEĞİ

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Engellilerle ilgili yürütülen çalışmalardan verimli ve etkili sonuçlar alınamamaktadır. Engelliler ve ailelerinden devlet idarecilerine kadar ilgili uygulamalarda kendini gösteren bu durumun ortak özelliği, teoriyi pratiğe dönüştüren kişilerin aynı toplumun üyeleri olmalarıdır. Bu durumda, her kesimden insanın hayata geçirdiği engelliliğe ilişkin toplumsal ve kültürel algı ve anlayış bu durumun temel nedenlerindendir.

Bu çalışmanın bulguları, Ankara’da yaşayan görme engelli genç bireylerle sekiz ay yürütülen etnografik bir araştırmaya dayanmaktadır. Çalışmada toplumun engellilere ilişkin temel sosyal ve kültürel yaklaşımlarına ulaşabilmek için engellilik, aile, eğitim, iş yaşamı, toplum ve devlet alanlarında üzerinde durulan sorunların ortak nedenleri görme engelli genç katılımcılar için belirleyici olan faktörler ışığında analiz edilmiştir.

Bu araştırmada engellilerle ilgili uygulamaların verimsiz ve etkisiz olmasının temel sosyal ve kültürel sebeplerinin, sadece-yardım yaklaşımı, muhtaç engelli varsayımı ve engellilerin görünmezliği olduğu sonucuna ulaşılmıştır. Bu çalışmanın önerdiği bir kavramsallaştırma olan sadece-yardım yaklaşımına göre, engelliler ile ilgili yapılabilecek tek şey onlara yardım etmektir. Toplumda hakim olan bu yaklaşım, kalıcı çözüm seçeneğine yer bırakmadığından, engellileri toplumsal yaşamda muhtaç ve görünmez olarak inşa etmektedir. Aynı zamanda, toplumsal yaşamın dinamikleri sonucu, tıpkı bir kısır döngü gibi, engelliler hakkında yanlış bilgi ve kavramlarla çerçevelenmiş farkındalık eksikliğinin, yani engellilerin görünmezliğinin, sadece-yardım yaklaşımını yeniden ürettiği sonucuna varılmıştır.

Anahtar Kelimeler: Engelliler, yardım, görünmezlik, verimsiz uygulamalar, gündelik yaşam

To Ayzade...

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LIST OF ABBREVIATIONS

Altı Nokta	Six Dots Association of the Blind
CRPD	Convention on the Rights of Persons with Disabilities
EKPSS	Disabled Public Personnel Selection Examination
Enuygar	Disabled People Application and Research Center, Istanbul University
EU	European Union
Eurostat	The Statistical Office of the European Union
EYHGM	General Directorate of Disabled and Elderly Services
GETEM	Boğaziçi University Technology and Education Laboratory for the Visually Impaired
MEB	Ministry of National Education
METU	Middle East Technical University
ODED	Middle East Barrier-Free Education Association
ÖSYM	The Measuring, Selection and Placement Center
ÖZİDA	The Presidency of Administration on Disabled People
RAM	The Guidance and Research Center
SIS	The State Institute of Statistics Prime Ministry Republic of Turkey
Turkstat	Turkish Statistical Institute
UN	The United Nations
UNESCO	The United Nations Educational Scientific and Cultural Organization
WHO	World Health Organization
YÖK	The Counsel of Higher Education

CHAPTER 1

INTRODUCTION

Disability is a socially constructed phenomenon. The meanings that are socially attributed to a physical or mental disorder and the assumptions as well as understandings about those who experience this condition determine the approach and behavior to disabled people and constitute socially experienced disability. Therefore, how the society reacts to a disabled person is an indicator of how disability is perceived by the society. Disabled people, their families, those people in their schools, managers and coworkers at workplaces, people on the streets and even the practitioners of the laws and state apparatus are all members of the same society. Therefore, a society's cultural and social understanding and perception of disability is the basis of people's reactions and behaviors towards disability both in one-to-one contacts and in the conceptual context. In other words, it is basically social and cultural factors that determine the approach of people living in the same society to disability.

The position of the persons with disabilities in social life is determined by society's perception and understanding of disability, its approach, perspective and behaviors. The life quality of persons with disabilities has a direct relation with that social situation of disability. Because, what all social institutions, from family to the state, performed about disability issues will be formed within the framework of and sourced by social perspective and related cultural codes towards disability as well as assumptions about disabled people.

There are contradictions and inconsistencies in the activities carried out regarding disability issues in the society, thus, efficient and effective results cannot be obtained. It is possible to see this situation as common in the disabled, their families, educational and working opportunities and the practices of the state in this regard, that is, in the activities of almost every segment of the society. This situation can be explained with concrete examples from the practices of the different institutions that compose the society. Today, it is stated that the legal and official regulations on disability in Turkey is quite extensive and adequate in most respects(Çitil & Üçüncü, 2018; Gökçek-Karaca, 2019; Şişman, 2011; Tansuğ, 2009). However, the problems in the implementation of these regulations are one of the most discussed issues in the field of disability(Aysoy, 2004; Aysoy, 2008; Azarkan&Benzer, 2018; Bezmez, 2013; Çağlar, 2011; Çitil & Üçüncü,2018; Erten&Aktel, 2020; Gökçek-Karaca, 2019; TOHAD, 2015). It is thought that people help the disabled on the street and

there is a sensitivity about disability in the society. Whereas, although twelve out of every hundred people are disabled(The State Institute of Statistics[SIS], 2002), persons with disabilities do not appear on the streets or we do not come across disabled people as much as they actually exist in social life. It is said that disabled children also benefit from the right to education thanks to the inclusive education applied in schools as well as special education centers. However, 60% of people with disabilities withdraw from education life before they finish secondary school(UNESCO, 2017). It is reported that there is an increase in the employment of disabled people with positive discrimination regulations. But, the unhappiness of working disabled young people in their workplaces is frequently mentioned. It is stated that families take care of their disabled family members. Conversely, the unconsciousness of families about disability is one of the most common discussion subjects. The disabled people live in line with the cultural perspective and social approach of the society, although there is a great cultural gap in transferring their own experiences lived to the society.

As a result, there are inefficiency in activities aimed at improving the daily lives of people with disabilities, and there are inconsistencies between the statements about the disabled or discourses on disability and their implementations. In addition, it would not be wrong to state that disabled people are invisible, both physically and metaphorically, to the extent that they actually exist in social life. The common feature of this inefficiency and inconsistency, which manifests itself in the disabled, their families, their education and business environments, and even in government practices, is that the people who put theory into practice, that is, those who practice it, are members of the same society. In this case, the social and cultural perception, understanding and perspective of people from all walks of life towards disability should be one of the main reasons for this inefficiency and ineffectiveness. It should also not be overlooked that there may be a direct relation between the invisibility of the disabled and these inefficient and ineffective results.

This inferences of both inefficient activities and the inconsistencies as well were reached with the information obtained from the families of disabled children as a result of the preliminary field studies of the thesis at first. So, accordingly, the study proceeded in the light of this information. Inefficient practices on disability issues in social life may have interrelated social, cultural, economic, political, governmental, familial and personal causes and consequences. In this study, the subject was researched based on the daily life experiences of disabled people by focusing on social and cultural reasons. Thus, the question that arises in this context was, what are the main social and cultural reasons for the inadequacy and ineffectiveness of activities aimed at improving the daily lives of people with disabilities?

The state guides disability related activities in the society in Turkey. Correspondingly, especially since the 2000s, within the framework of social policy laws and regulations, disability studies have gained momentum in parallel with state initiatives. In addition, legal regulations affect the approach of almost every social institution, from family to education, and thus the daily life of individuals with disabilities. For this reason, it will be useful to summarize the developments related

to disability in the context of the state in terms of defining the background and questions of the research.

The social model is officially applied in Turkey(The Presidency of Administration on Disabled People [ÖZİDA], 2010). One of the most important achievements of the social model is the rights-based approach, which is essential for improving the quality of life of people with disabilities. Accordingly, as stated in the literature review section, in the 1950s, besides some legal regulations, associations for the disabled were established with the initiative of the state and personal efforts. Especially in the 1980s, more active and systematic studies were observed. With the entry into force of the disability law in 2005, there have been serious developments in this regard. Nevertheless, researches reveal that social model and the rights-based approach cannot be internalized in social life and even not sufficiently adopted by people(Aysoy, 2004, 2008; Azarkan & Benzer, 2018; Bezmez, 2013; Bezmez & Yardımcı, 2013; Çağlar, 2011; Çitil & Üçüncü, 2018). Therefore, it is necessary to investigate and uncover the reasons why rights-based approaches are not reflected in practice, that is, in the everyday life of persons with disabilities.

Hence, the road map of the research was not constituted to offer some solutions to the disability related problems. But the research was designed to investigate the social and cultural causes of the issues in the frame of daily living of disabled people and trying to make them visible. Because in the relevant literature, generally, the problems that arise as a result of the activities about disability are mostly researched and examined. However, there is a gap in the investigation of the cultural and social sources of these problems especially based on disabled people's experiences.

The data that was first noticed when the subject of disability was examined is that; the proportion of disabled people to the population is 12%(SIS, 2002) Therefore, another issue that arose along with the preliminary studies was that, disabled people are not physically and metaphorically visible in social life. Then, why are disabled people invisible? There must be a connection between the source of the main social and cultural causes of ineffectiveness in practice, that is, in the practice of everyday life, and the invisibility of the disabled. Investigating the fundamental social and cultural causes is an extremely broad and multi-layered subject. Therefore, this research was limited in the context of the invisibility of the disabled and the participants of the fieldwork.

One of the purposes of the study was searching the fundamental social and cultural perspectives, understandings and approaches that are claimed to cause inefficient practices in disability-related issues in the frame of invisibility. The other purpose was trying to contribute the transfer of the experiences of disabled people to academia and society. Because, disability is a field of research that has been studied very few in social sciences and especially in social anthropology in Turkey.

The society's approach to disability issues naturally have been internalized by the disabled, who are also members of the society. Hence, they may shape their lives according to this perception and acceptance. In addition, as a part of society, persons with disabilities are the most informed people

on this subject. For this reason, the study was designed to reach the answers of the research's questions from daily living experiences of disabled people. Additionally, experiences in social life on disability, which is an extremely complex and wide field, may differ according to the disability category. For this reason, the study was conducted with visually impaired young individuals who continue their university education or are preparing for the university entrance exam.

Before the fieldwork, the main subjects and general framework of the study were determined. That is, the questions I was looking for answers to, and some inferences or arguments in need of confirmation were evident in my mind. However, this was just general framework of the study. Because, the research was planned to be able to recognize and understand the experiences of the visually disabled people, and thus to grasp the social reality, without limiting it as much as possible. For this purpose, participant observation and in-depth interview techniques were chosen as fieldwork.

The participant observation process lasted about the eight-month period when I was a volunteer teacher at *Orta Doğu Engelsiz Eğitim Derneği* (Middle East Barrier-Free Education Association[ODED]) which was a non-profit education association in Ankara. The association supported visually impaired students who were studying or graduated from high school to prepare for the university entrance exam. In this process, eight visually impaired individuals, three female and five male, aged between 18-22 attended university preparation courses at ODED. Additionally, other people who always there were, family members of the visually disabled students, some of former students, other sighted volunteer teachers and the association's managers. In addition to giving lectures to visually disabled students, I had chance to spent time with them while shopping, picnicking or celebrating some events inside and outside the association place.

The participant observation period, which enabled me to join them in daily lives of visually impaired young people at an important turning point in their lives, was also provided me to understand them and their experiences lived. Additionally, I observed their communication with each other, with their immediate circle and with the society at large. Therefore, during the participant observation process, I had the opportunity to catch the cultural perspective and social approaches that are not noticed in the routine of daily life but are important and decisive for the young people with visual impairment.

The interviews were conducted in forms of unstructured and semi-structured in-depth interactions. The narratives referenced to the analyzes in the findings chapters were mainly based on semi-structured in-depth interviews. In addition to this, expert interviews were also conducted. Besides, as the nature of participant observation, unstructured interviews and group interviews contributed to the research.

Semi-structured in-depth interviews were held with 15 visually disabled people (nine female, six male) between ages of 18-23 living in Ankara who were university students or preparing for the university entrance exam. They were all single and living with their families. The questionnaire consisted of 53 open-ended questions and in addition to these, sub-questions prepared to be asked

according to the first answer given if necessary. The main topics of questions were personal information, everyday life, education, family and relatives, working life, social life, disability perception and definition, the state, non-governmental organizations and the society. In addition, the interviewees were asked about their knowledge and experiences about people with other types of disabilities related to each topic.

Thus, the experiences of the participants were analyzed in a very broad scope in order to reach the basic understandings and perspectives of the society on the disabled within the framework of the relevant subject. As a result, the common causes of the issues stated in all these areas were tried to be determined in the light of the factors that were important and decisive for the visually impaired young participants.

Disability is one of the very least studied fields in social sciences in Turkey, in addition there is a huge cultural gap in the integration of the experiences of people with disabilities into society. In this study, information was obtained on social reality and the issues that are decisive for the disabled based on the daily life experiences of the visually impaired young participants. Therefore, it is hoped that the data, findings and analyzes obtained by ethnographic methods in this research will contribute to disability studies, social sciences and the society.

The thesis was organized into six chapters. In this first chapter, Introduction, the perspective of the study, the background, aims, main questions and the significance the study were stated. In addition, the methods of seeking answers to the questions, the content and scope of the literature review, the main headings of the findings and the conclusion sections were included.

The 2nd chapter is Literature Review with its subsections as Disability Studies and Studies on Visual Disability. In the first subsection, disability studies in general in the world and in Turkey were briefly summarized in the historical context. In the second subsection, the definition of visual disability was given and developments and related debates about disability in Turkey were examined in the context of visual disability. For the purposes of the research, the main references in the findings of the thesis were the statements of the participants. However, the literature review constituted a large part of the study, both because the subject of disability is an interdisciplinary field of study and because the research was based on daily life, which naturally includes many agents. Before the fieldwork, the disability movement in the world and the studies on disability in Turkey were examined in historical context. The relevant approaches, definitions, concepts, themes, prominent discussions and gaps in need of research were identified. After the field study, more recent related studies in the literature were searched in the light of the findings. In addition, legal and official sources were also reviewed, as they gave direction to the disability movement and studies in Turkey. Besides, the literature on visual impairment was also examined. The literature review focused on cultural and social anthropology, sociology and social policy in the context of disability studies. Besides, as a requirement of the research, written sources including themes such as society, education, family,

working life, social life, daily life, disability perception and definition, state, non-governmental organizations based on disability were also examined at large.

The 3rd chapter, Methodology, consists of six parts. In the first subsection, the aims of the study were explained within the framework of the research questions and how they emerged and progressed. In the next part, the strategy and design of the research were explained by giving information on the strategy of accessing data, the framework and content of the research. In the following section, the participant observation period and then the interviews of the study were detailed. The participant observation process was described in terms of people, the space, and its contribution to the study. In the following section, detailed information about the unstructured and semi-structured in-depth interviews and the interviewees were given. In the next part, the analyzing and writing phase of the thesis was explained. And, the last part was consisting of restrictions and limitations of the study both in the frame of limitations of the collected data and subjects which were excluded in the findings chapters.

The 4th chapter was titled as Help-only Approach. The findings that laid the ground for this study's offered conceptualization of the Help-only approach(sadece-yardım yaklaşımı), and what was meant by this concept were explained based on the experiences of visually disabled participants. According to the findings of this study, it was determined that society's approach to disabled people is based on help-based perspectives and practices arising from its own cultural and social characteristics. It has therefore been proposed to conceptualize this approach as the "Help-only approach". The research revealed that help-only approach, which has been internalized and implemented by different segments of the society, builds the needy disabled assumption and also the invisibility of the disabled. This situation was detailed in sub-segments with sub-titles of Family: Oppressive-protectionist Help, Social Encounters: People on the Street, Education: Optional Self-sufficiency Training, Workplace : Income-only Practices and State: from Disability Rights to Help-based Practices. In these subsections, cultural and social basis and consequences of help-only approach were detailed through the participants' experiences lived. That is, how this approach was implemented by persons with disabilities, their families, people in education and work places, people on the street, public regulations, and how it was reinforced and reproduced in social life was demonstrated through the experiences of participants conveyed from their daily lives.

The 5th chapter was headed as the Construction of Disabled as Needy and Invisible. Firstly, the invisibility as a concept was explained and the relations between invisibility of the disabled, the needy disabled assumption and the help-only approach were detailed. Then, the necessity of investigating invisibility of people with disabilities instead of invisibility of "disability" was demonstrated through people's reactions to direct financial supports obtained from the state. The first sub-section of the chapter was headed as To Be a Needy Disabled Through White Cane. One of the most concrete examples of the construction of the needy disabled assumption in society is the perspective to the white cane which is essential for independent movement of visually disabled

people. In this context, the approach and practices of persons with visually disabled to white canes and related accessibility issues necessary for the effective use of the canes have been analyzed. Then, in the Invisibility of the Disabled part, at first, the lack of information about disabled people in the society was revealed through the behaviors towards the participants in general and the participants' perceptions on people with other types of disabilities. Secondly, misinformation and misconceptions about disabled people were analyzed based on the society's approach to the day and week of persons with disabilities. In the Visibility of the Disabled People subsection, the situation of visibility of the disabled with practical individual and spatial context was described with examples by looking at the issue in reverse. Because, in order to embody the “invisibility of disabled people”, it is necessary to point out the effect and some consequences of the “visibility” of the disabled on their social lives.

The 6th chapter consists of Conclusions and Suggestions of the research. In this last chapter, the findings and conclusions drawn from the participant's experiences described in detail were summarized and suggestions on the relevant issues were stated within the framework of the purposes and initial claims of the research.

CHAPTER 2

LITERATURE REVIEW

The literature review of the research was carried out in two stages. Before the field study, first of all, a general written source research was made. In the second stage, the literature was reviewed in the light of the findings obtained after the field study. Before the fieldwork, the disability movement in the world and disability studies in Turkey were examined in the historical context, and relevant approaches, definitions, concepts, themes, prominent discussions and gaps needed to be researched were identified. After the field study, more recent related studies in the literature were searched in the light of the findings. In addition, legal and official sources have also been scanned, as they largely shape the disability movement and its work in Turkey.

This chapter consists of two parts based on written sources in English and Turkish. In the first part, disability studies will be briefly summarized in the historical context, and in the next part, studies on the visually impaired will be reviewed.

2.1 Disability Studies

Mainstream disability studies emerged and developed from Anglo-American perspective against individualistic medical model as the disability rights movement. To the medical model which dominated disability policy and service provision before, in brief, disability(impairment) taken as a personal tragedy which can be cured or treated only by medicine and rehabilitation. Thus, “The medical view of disability tends to regard disabled people as ‘having something wrong with them’ and hence the source of the problem”(Oliver, 2004:20). Consequently, in medical model disability was considered only as a physical or mental disorder of a person whereas social and environmental barriers were neglected.

Against this perspective, the Social Model which has been crucial to the disability movement since 1970s, emerged from the intellectual and political arguments of the Union of Physically Impaired Against Segregation which was a disability rights organization in the United Kingdom. Disability also raised as a human rights issue in global public discourse after the proclaimed of 1981 as the International Year of the Disabled by the United Nations[UN](Meekosha&Shuttleworth, 2009).

In the following decades, people with disabilities and their allies in many countries organized against the historical oppression and exclusion to which they were subjected. The key to these struggles was the challenge to over-medicalized and individualist accounts of disability. That is, as Tom Shakespeare(2006) states;

While the problems of disabled people have been explained historically in terms of divine punishment, karma or moral failing, and post-Enlightenment in terms of biological deficit, the disability movement has focused attention onto social oppression, cultural discourse, and environmental barriers(p.197).

Therefore, Social Model enables disabled people to reject individual bodily or mentally deficit and assert their rights to equality, addressing issues of marginalization, oppression and discrimination. The Social Model discourse identifies the need for barrier removal which gave disabled people a political strategy based on civil rights in the name of disability rights.

But, especially when it comes to 2000s, some weaknesses of the social model and the need to go beyond it have begun to be debated in the literature. The Social Model has come to be criticized for ignoring the body and the effects and experiences of the impairment. Additionally, it has failed to include all people around the world with impairment and related with that fails to take account multiple oppression like disadvantages of gender, race, age and sexuality. Also, in this period, studies from the global south and the majority world are being added to the disability studies that have expanded in parallel with the criticisms of the social model(Meekosha & Shuttleworth, 2009).

To put a different way, the medical model considered disability as a physical or mental disorder of the individual and focused on its treatment and rehabilitation. In contrast, although the social model based on the rights-based approach provides important gains regarding the social life of the disabled, it has been criticized for ignoring the personal experience of disability and thus the scope of disability caused by physical or mental disorder. In addition, the fact that the disability in social life is evaluated only in the context of the region where the model emerged, not taking into account the different lifestyles in different parts of the world, was seen as a deficiency of the social model.

Because, it is possible to say that the experience of impairment is universal. But, how it is reacted within a particular society varies according to different cultural areas and settings. Even what disability is or what counts as a disability depends on the culture and the society. Approximately 80% of 1 billion disabled people in the world live in the so-called Global South(Friedner & Zoanni, Grech & Soldatic, Staples & Mehrotra, cited in Ginsburg & Rapp, 2020; WHO, 2011). In addition, when turning the spotlight from global North to global South, "Unlike rich countries, the major causes of disability in these countries are childhood illnesses such as measles and cerebral malaria. Mothers have to keep the family fed and healthy"(Encyclopedia of Disability, 2006:713). Therefore, mainstream disability studies were criticized for not addressing issues of non-Western areas as well as ignoring different cultural settings.

Scheer and Groce(1988), for instance, emphasize several ethnocentric assumptions about disability studies that were emerged as the result of “the relative lack of attention paid to a cross-cultural or historical perspective”(p.23) in social sciences including anthropology at their early review of ethnographic data on disability. They emphasized that, however there was not any report to verify, it is assumed that disabled individuals born outside the industrialized world were either killed at birth or died when young. They pointed out that, on the contrary, an impaired person was like any other member integrated into community roles, protected by ties of kinship and participation in wider social networks than a member of a “complex” society. Therefore, an impairment is not only one social identity of a person in a small community as it is mostly perceived in an industrialized society where relations between people are mostly individualistic(Scheer & Groce, 1988).

Thus, critical disability studies, which both criticize the social model and emphasize its deficiencies, therefore suggesting more comprehensive and different perspectives on the subject have begun to come to the fore. For instance, Ingstad and Whyte have drawn attention to the Global South with their two highly influential reviews, *Disability and Culture*(1995) and *Disability in Local and Global Worlds*(2007) in anthropology as well as disability studies with their cross-cultural perspective(cited in Ginsburg & Rapp, 2013, 2020).

It should be noted that, today, disability studies are in a much more comprehensive and inclusive period. Because the effects of different cultural understandings on disability are examined both with different perspectives on the social model and with a critical approach. It is this approach that forms the theoretical framework of this study. That is, according to Meekosha and Shuttleworth in 2009, critical disability studies will inevitably build on the work of the early pioneers in disability studies and continue to employ relevant aspects of social models of disability(Meekosha & Shuttleworth, 2009). To Mallett and Runswick-Cole in 2014, critical disability studies challenge the dominance of the concerns of the Global North within Disability Studies, move away from the preoccupation with binary understandings (disability versus impairment) and welcome the ideas from cultural studies and humanities writing about disability(Mallett & Runswick-Cole, 2014). And, according to Dan Goodley et.al in 2019, the Critical Disability Studies scholarship should not be considered as a rejection of the preexisting disability studies theory. Because,“the arrival of Critical Disability Studies is testimony to the maturity of a field that has built upon foundational knowledge and recognizes that complex sociopolitical times require an opposite response”(Goodley et.al, 2019:989).

Some of these approaches are, the Nordic Relational Model, the North American Minority-group Model and the Australian Perspective. According to the Nordic Relational Model, environmental factors are the main determinants of disability. Tøssebro(2004:4) explains the issue of disability and the environment as follows;

Disability has been defined as a mismatch between the person's capabilities and the functional demands of the environment or in terms of a gap between individual functioning and societal/

environmental demands. Disability is thus a relationship, and it is relative to the environment. It is also situational rather than an always present essence of the person: A blind person is not disabled when speaking on the telephone, and is exceptionally able when the lights have gone out.

The North American Minority-group Model is based on the traditions of radical feminism, the black American civil rights movement and the gay, lesbian, bi- and transsexual movement. This model emphasizes the roles of “norms” and “normal” in creating exclusion and prejudice, and minoritisation of disabled people(Mallett & Runswick-Cole, 2014).

The Australian Perspective, has counted in some important theoretical concepts such as “ableism” into disability studies. This perspective makes a critique over the understanding of disability from the window of “ableist” thinking in general and examines the results arising from this understanding. Fiona Kumari Campbell(2012:213) explains ableism as;

Ableism refers to a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then is cast as a diminished state of being human.

Therefore, to her, an ableist perspective might suggest that in a democracy people with disabilities should be treated fairly on the basis of “tolerance”. However, such a stance does not imply that disability is viewed as a reasonable and acceptable form of diversity. Ableist thinking is based on the assumption that all disabilities are unacceptable, regardless of type or degree.

Besides those general perspectives, the source of disability perception has been discussed in the context of some basic social acceptances and concepts like family and normality. Joan Ablon(2002), whose pioneering ethnographic studies were one of the important factors in the establishment of anthropology of disability, emphasizes the importance of family for creation and overcome processes of stigma for the people with disabilities. To Ablon, unconditional family support and clear intrafamily communication are major features to cope with the stigma. But, she also pointed out that;

Stigma may be created and nurtured by negative attitudes and statements by the family, children in school and the neighborhood, and doctors and other medical personnel, as well as through the larger social contexts of public opinion and values, media representations, and impersonal social interactions... Family attitudes can be particularly destructive(2002:4).

Family is a socially constructed phenomenon as the disability. Therefore, what is understood as family in the mainstream society directly affects families that have a disabled member. That is, nuclear family is assumed as the “norm”. This “normal” nuclear family consist of a formally married heterosexual couple and their children which are all “able” people in addition to its other specifications. To this assumption, a family is a peaceful, respectful and supportive space for its all members in any case where gender-based division of labor is settled. However, the actual family practices show that it is not always the case. Karçkay(2002) states through examining of nine disabled person's families that family members' social stereotypes about disabled people affects the disabled

peoples' own perceptions about themselves. Additionally she wrote that “families see the existence of their disabled children as a loss rather than accepting their originality and talents, feel shame and reflect those negative emotions and beliefs to their children”(p.145,my translation).

On the other side, care-giving to a disabled person is almost always perceived as the responsibility and obligation of the family members, especially mothers, as a part of "the duty" of being a family and a mother. As it is well-known, mothers are primary caregivers to a child with disability within the family as it is the same for a not-disabled one. But, different from a non-disabled child's mother, care-giving is a life course process for a mother especially with a child with disability.

Additionally, ascribing the care-giving responsibility solely on the family has a backing effect on the perception of disability as a “personal tragedy” rather than a socially constructed phenomenon. Therefore, “mapping how families express their support and care of children and relatives with disabilities dominate in the literature”(Encyclopedia of Disability 2006:708). It is also needed to be noted here that one of the most important reasons of this is the studies of scholars who are mother of a disabled child. Disability has become more visible within the academia and also society thanks to those social scientists' studies.

For instance, Landsman(1998) who is a scholar and a mother of a child with cerebral palsy emphasizes that “while in many societies a child is understood to be the embodiment of the parents' relationships with each other, and with other kin, with the development of new reproductive technologies, children become the embodiment of their parents' choices”(p.77) not obligation. Under this circumstances mothers of children with disabilities have to face with circumstances that devalues their children as well as their motherhood. But, the question is what constitutes a life worth living? Landsman(1998) reveals how mothers revise the concept of “normal” as well as “perfect” baby in their society through their own experiences of mothering in her study.

Rapp and Ginsburg(2001,2010,2011,2012) contribute the literature with their feminist and critical anthropological perspective beginning from their own experiences about their children with learning difficulties. They analyze parents' experience of having and raising a disabled child by revealing that cultural expectations of perfection and health in individuals and families are intertwined with parents' circumstances. They examine how the private narratives and experiences of American parents expecting or raising an “anomalous” baby interact with the mainly negative public narratives of disability. They emphasize the importance of family that have a member of disabled to construct a meaningful understanding of life with a difference. This also provide a way to interrogate so called “perfect” child, parenting and family. They also suggest that disabled people's and their families' experiences would increase the awareness of the disability as much as those experiences get involved into the society. They also pointed out that, since 2000s anthropologists have contributed to disability studies with their ability to examine experiences lived through ethnographic methods(Ginsburg & Rapp, 2013).

Those above mentioned concepts such as “normality” is one of the main emphasizes on the fact that public perception about disability has more fundamental problems. The Disability Studies Readers’ editor Lennard J. Davis(1997,2006,2010,2013,2017,2021) who was raised by his deaf parents states that “the problem is not the person with disabilities; the problem is the way that normalcy is constructed to create the problem of the disabled person”(Davis, 2013:1). He also reveals the historical baseline of the concept of "normal" in Europe, stating that there was not a concept of the “norm” or “average” in European culture before the 19th century. According to Davis(2013), after industrialization, the spread of statistics(bell curve) and eugenics, both of which are directly related and supported each other, imposed the average human body and intelligence, in other saying, norms of human which eventually give rise to “deviations”. And he emphasis that “when we think of bodies, in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviant”(p.3).

Approaching the issue from a historical perspective based on specific disability categories has also contributed to disability studies. These studies provides insight into the historical development of disability issues in societies from where the social model as well as disability rights-based movement were developed. For instance, Stiker's(2002) book *A History of Disability* that contains developments and studies in perception and practice regarding mental disability from pre-enlightenment period to the present, especially in France, generally in the West. Wright's(2011) book *Downs - The History of a Disability* also reveals the history of mental disability in English-speaking countries by focusing on Down’s syndrome since the 1600s.

One of the studies from a historical perspective in Turkey is Rüya Kılıç(2013)'s *Deliler ve Doktorları - Osmanlı'dan Cumhuriyete Delilik* (Insane and Their Doctors - Insanity from the Ottoman Empire to the Republic, my translation) based on her the History doctoral dissertation about treatments and rehabilitation process of insanity¹. By researching archives, written and visual sources, the author revealed the experiences of the patients(people with mental disability) in daily life of the period, the perception and reaction of their families and society. Kılıç’s book provides an historical look to the intellectual disability in Turkish society. One of the other studies in this field is, Fatih Artvinli’s(2013) book titled *Delilik, Siyaset ve Toplum, Toptası Bimarhanesi (1873-1927)* [Madness, Politics and Society: Toptasi Lunatic Asylum (1873-1927)]. Artvinli reveals the process of modern psychiatry's inclusion in Ottoman medicine and the institutional efforts for the protection and treatment of mad people are explained in detail(cited in Gündüz, 2014:13). When all these studies are evaluated together it is also a way to see historically the differences and similarities in the perspectives of these cultures in different geographies where disability is experienced.

Historically, in Ottoman society the state created positive opportunities for disabled people(Gündüz, 2014; Sağlam-Tekir, 2016) and in the early periods of the Republic, more systematic

¹The separation of mental retardation or mental disabilities from psychiatric illnesses is fairly new in medicine, society and daily life.

and institutional policies began to be produced (Subaşıoğlu & Atayurt-Fenge, 2019). However, significant and comprehensive developments took place after 1950, especially with the establishment of the very first disability related association in Turkey, Altı Nokta Körler Derneği (Six Dots Association of the Blind [Altı Nokta]). But, after all, it is not possible to say that there is a disability literature which evolved together with disability movement and its experiences in Turkey.

The reasons why a disability movement has not been formed in Turkey may be that there is no rights-based movement tradition in Turkey, or disabled people's having been culturally one of the interlocutors of philanthropic institutions and behaviors. In addition, it should be noted that, as Davis (2013) pointed out for 19th century industrialized European society, there was no imposed "human norm" or widespread "eugenics" in Turkey. So, it is possible to say that there was no structural oppression on the disabled which would be created a counter-movement like the disability movement that started in England.

Ultimately, there was not a distinctive perspective of disability movement in Turkey which was held commonly by disability organizations, associations, the academy as well as by people with disabilities. On the contrary, disability studies gained momentum parallel with the governmental initiatives especially since 2000s in the frame of the social policy codes and regulations. The developments regarding these social policy arrangements are in line with the full membership negotiations processes began in 2005 with the European Union [EU] and the adoption of UN Convention on the Rights of Persons with Disabilities [CRPD] in 2006². In addition, Turkey - EU financial cooperation may also have an effect on the disability movement and studies in Turkey (Ministry for EU Affairs, 2014).

The state's "formal" perspective of disability is The Social Model (ÖZİDA, 2010). This perspective is welcomed and followed by the relevant institutions, academia and the society. Considering all this, it is needed to emphasize that the state's implementation is one of the determining factors in the examining and solution of disability issues as well as guiding the society on disability movement. Correspondingly, disability studies inevitably evolve in this context. Therefore, the source of state practices, namely legislation and regulations, needed to be viewed in order to understand both the focus and direction of disability studies as well as disability movement in the country.

Some of the main legal bases of the services related to the disabled today are The Constitution (1982 Anayasası), Social Services Law No:2828, 1983 (Sosyal Hizmetler Kanunu), Decree Law on Special Education No. 573, 1997 (Özel Eğitim Hakkında Kanun Hükmünde Kararname), and the Act on Disabled No. 5378, 2005 (Engelliler Hakkında Kanun). In addition, special regulations for the disabled are included in the Turkish Civil Code, Social Insurance and General Health Insurance Law, Labor Law, Civil Servants Law, Municipal Law and Health Services Basic Law. But, the international and national regulations on the rights of persons with disabilities and the obligations of the state in this

² Turkey is obliged to comply with regulations relating to social policy and social services in the European Union's *acquis* in the field of disability in the European Union context (Gökçek-Karaca 2019:28, my translation). According to the method of the Constitution, international treaties put into effect have the force of law (Gökçek-Karaca 2019:29, my translation).

field are scattered in the legislation(Çitil & Üçüncü, 2018; Gökçek-Karaca, 2019; Şişman, 2011; Tansuğ, 2009).

The Act on Disabled entered into force in 2005 is the first law enacted directly for the disabled. As a note, in addition to disabled associations, established with the initiative of the state since the 1950s, like Altı Nokta and *Türkiye Sakatlar Derneği* (Turkey Disabled Association), and also decisions made in *1.Özürlüler Şurası* (1st Disability Council) in 1999 carried out by *Özürlüler İdaresi Başkanlığı* [ÖZİDA] (The Presidency of Administration on Disabled People³) made significant contributions to the recognition of disability in the public sphere, and thus to the formation of the disability law(Burcu, 2015; Yılmaz, 2014.).

The Act on Disabled has brought changes to many different laws. The act led to the expansion of the social policy area of the disabled especially in the field of public expenditures, like a noticeable increase in the salary of the disabled and free use of special education centers. In addition, obligation to employ disabled people in workplaces became operational(Yılmaz, 2014). The purpose of this law, which is stated to cover the disabled, their families, institutions and organizations providing services for the disabled, and other relevant persons(5378 Act,matter 2) is written as;

Prevention of disability, solving the problems of disabled people related to health, education, rehabilitation, employment, care and social security, to ensure their participation in the society by taking measures to ensure their development in all aspects and to eliminate the barriers on them, and to make the necessary arrangements for the coordination of these services.(5378 Act,matter1, my translation).

Although the laws are at the top in writing, relevant and necessary regulations should be put into effect while approaching daily life. Furthermore, the inclusion of disability rights in legislation is a start, decisive and determinant, but it must be enforceable and put into practice. Therefore, however there may be regulations on rights-based approach, the problems in implementation remained the subject of discussion in studies especially in law, social policy, public administration and education fields of studies.

The necessity of increasing the effectiveness of the law and regulations in practice(Erten & Aktel, 2020; Gökçek-Karaca, 2019; TOHAD, 2015) is one of the most common subjects of these discussions. In addition, disability rights(Aysoy, 2004; Aysoy, 2008; Azarkan & Benzer, 2018; Bezmez, 2013; Çağlar, 2011; Çitil & Üçüncü, 2018), discrimination(Çağlar, 2011; ÖZİDA, 2010), education(Aysoy, 2004; Bayhan & Sipal, 2011; Çağlar, 2009; Çitil & Üçüncü, 2018; Demirtaş, 2019; Şirin, 2019), right of accessibility(Erten & Aktel, 2020; Çağlar, 2012; Şimşek, 2021; Türkbağ & Besiri, 2009; Yardımcı & Bezmez, 2018), employment(Aysoy, 2008; Gökçeoğlu-Balcı, 2009; Yılmaz,

³ Presidency of Administration on Disabled People was established under the Prime Ministry with the Decree-Law No. 571 of 25 March 1997, based on the Authorization Law No. 4216 dated December 3, 1996. The Institution, which does not have a provincial organization, continues its services under a state minister(ÖZİDA 2007:22) This institution took the name of *Özürlü ve Yaşlı Hizmetleri Genel Müdürlüğü* in 2011 and continued its activities as a central unit under the Ministry of Family and Social Policies. In 2013, its name was changed to *Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü* [EYHGM](General Directorate of Services for the Disabled and Elderly) and has been working under the Ministry of Family, Labor and Social Services since 2018 based on Presidential Decree on the Organization of the Presidency no 1, dated 10/8/2018(10/8/2018 tarihli 1 sayılı Cumhurbaşkanlığı Teşkilatı Hakkında Cumhurbaşkanlığı Kararnamesi)(EYHGM 2021).

2014) and social policies(Yılmaz, 2014; Yılmaz & Yentürk, 2017) are other themes which are most discussed subjects in the frame of the problems in implementation of laws and regulations.

All these studies reveal that although the rights of the disabled have legal grounds, there are serious problems in practice and the reasons for this need to be investigated. It would not be wrong to say that studies conducted in the context of disability focus on these problems rather than the causes of these problems. Investigating and making problems visible provides important contributions to the literature. However, there are very few ethnographic studies on the causes of these practice problems in general. For this reason, the social and cultural causes of these problems, which is one of the aims of this research, should be emphasized and investigated.

One of the other inadequacies regarding disability subject is the lack of a comprehensive and up-to-date statistical database on disabled people, which negatively affects disability studies(Burcu, 2015; Çakıroğlu & Melekoğlu, 2014). Even so, two surveys in particular provide significant data for disability studies. One of these, *Türkiye Özürlüler Araştırması 2002* (Turkey Disability Survey, 2002) is the first and most comprehensive research on the quantitative and qualitative information about disabled population living in Turkey. In addition, for the first time information on the population with chronic illnesses is compiled in this survey(Demir & Aysoy, 2002). The other one, *Özürlülüğe Dayalı Ayrımcılığın Ölçülmesi Araştırması* (Survey on Measuring Disability Discrimination), has identified the experiences of disability-based discrimination in various areas of social life through a questionnaire prepared within the framework of the UN CRPD. The Social areas subject to the survey are education, work and employment, health field, political rights, access to justice, participation in recreational and leisure activities, inclusion in society, access to information(ÖZİDA, 2010).

The studies on disability issues and disabled people are developing also within universities. Examining the number and content of thesis can give an idea about the scope of disability studies in academia, as summarised in Table 1. According to the lists in *Yükseköğretim Kurulu* (The Counsel of Higher Education[YÖK]) thesis center website nearly half of the master's and doctoral theses on disability are in the field of The Education and Training. This is followed by studies in the disciplines of Psychology, Social Work and Sociology. Besides, studies have been carried out in other fields like economics and home economics, public administration, law, religion and tourism⁴. In proportion to the total number of thesis of the relevant discipline, it is seen that disability is mostly studied in the fields of Social Work, Home Economics and Psychology (The Counsel of Higher Education[YÖK], 2021a).

Table 1:The fields and themes with the most theses on disability in the social sciences, April 2021

Numerically at most, respectively	Proportionally at most	Mostly studied themes
Education and Training Psychology Social Work	Social Work Home Economics Psychology	Family, parents and sibling relations Mothers of the disabled Disabled child, disabled care Education and training

⁴ YÖK Thesis Center website(<https://tez.yok.gov.tr/UlusalTezMerkezi/tarama.jsp>), Detailed Search: search criteria; includes in term(s) : "engelli" or "özürlü" or "sakat", search field:abstract, group:social sciences, in 21.04.2021

Sociology Economics Home economics Public administration Law, Religion, Tourism		Social policies, social services Discrimination
		themes added over the past decade
		Social exclusion Gender and women issues Right of accessibility

When disability studies are examined in general, it is seen that the studies are conducted in the context of family, disabled care, mother, parent and sibling relationships, disabled child, education, social policies, discrimination and social services. Additionally, there are also disability studies in the areas of architecture and urban and regional planning in the context of accessibility(Bezmez, Yardımcı & Şentürk, 2011). In addition to these subject matters, especially when the theses conducted in the last decade are examined, it is seen that the themes of social exclusion, gender and women issues, and right of access are added to these subjects intensively⁵.

In the field of anthropology, there are very few graduate theses on disability. The themes of the theses other than physical anthropology can be summarized as invisible disabilities, inclusion in culture, sociocultural characteristics of disable people, accessibility and aging(YÖK, 2021a). In general terms, there is a lack of studies that include detailed analysis of disabled experiences over daily life. In this context, it is hoped that this thesis will contribute to the literature.

Still, the studies on disability and disabled people carried out in last decade have shown serious acceleration in the academia. The effect of the increase in the population and also in the number of universities cannot be ignored, but it can also be interpreted as the disability started to be seen as an academic field of study. However, as Burcu(2015) states for the Sociology, there also has been a significant delay in considering the social dimension of disability in theoretical, conceptual and methodological context. In addition, the shift of these academic studies from the weight of individualistic medical discourse to the weight of social discourse corresponds to relatively recent times(Burcu, 2015).

One of the important developments in recent years is that, disability studies are being considered as an interdisciplinary field on its own in universities. The disability research and application centers are studying disability from the perspective of social life and living standards of people with disabilities. Examples of these developments in universities are as follows: The research and application center and an undergraduate and a graduate course named as *Engellilik Sosyolojisi* (Sociology of Disability) in Hacettepe University(Hacettepe University, 2021a, 2021b, 2021c), the research institute for individuals with disabilities in Anadolu University(Anadolu University, 2021a), *Engelliler Uygulama ve Araştırma Merkezi* (Disabled People Application and Research Center[Enuygar]) and disability research master program with thesis in İstanbul University(Enuygar, 2021). In addition, Boğaziçi University Social Policy Forum organizes with its allies the Disability

⁵ YÖK Thesis Center website(<https://tez.gov.tr/UlusalTezMerkezi/tarama.jsp>),Detailed Search, search criteria; includes in term(s) : "engelli" or, "özürlü" or "sakat", search field:abstract, group:social sciences, year;2010..2021 in 21.04.2021

Studies School education program for graduate students enrolled in Turkish universities who conduct or are planning to conduct research in the field of disability studies(Bogazici University, 2020).

Since disability is an interdisciplinary field, joint studies of different disciplines are very important in terms of informing the society about disability, raising awareness, identifying the problems of the disabled and searching solutions to these problems. One of the examples of interdisciplinary collaborations is the *1. Engellilik Arařtırmaları Kongresi*(1st Disability Research Congress) held on 24-25 November 2016 in cooperation with Enuygar and Hacettepe University Disabled Research and Application Center. Academicians from all disciplines working in the field of disability, educators, public and private sector representatives, non-governmental organizations, disabled individuals, families and students were invited to the congress. In the congress, where cooperation between disciplines and sectors was the aim, the subjects were determined as human rights and social justice, social policies, health and rehabilitation, education, employment, disability in old age, home care, accessibility, assistive technologies, history, literature and art, and media(Enuygar, 2016).

As Stiker(1999) emphasizes, disability is conceived according to the situation that prevails in each country or cultural area. And, for this reason, it is essential to examine disability not only theoretically or sociologically but also historically(Stiker, 1999). In this sense, an important event that deals with disability in its historical dimension was *Dünden Bugüne Engellilik* (Disability from Past to Today) Disability Research Conference. The conference was held in 2018 with Istanbul University Enuygar and Istanbul Metropolitan Municipality Health Department. In the conference, the history of disability in Turkish society was examined in the frame of sociocultural processes, institutional and legal history. The subjects of the conference; history of disability, developments in medicine, assistive technologies, special education, art and disability, accessibility and universal design, public management and social policies, civil society movements and activism, prejudices and discrimination, disability and immigration(Engellilik Arařtırmaları Konferansı Özet Kitabı, 2018). In addition, the book *Engellilik Tarihi Yazıları* (Essays on Disability History) compiled from the studies presented at this conference was published online in September, 2020(Aydın et al (eds), 2020).

Differently from published books, academic researches or articles in the context of literature of disability studies, it is needed to make mention of some intellectual people that come together, especially through social media, publish articles via the web page/forum and discuss issues about disability. In these platforms, in addition to sharing up-to-date information on legal rights, health problems and personal experiences, social life and daily life discussions are also held in the forums. Some of the topics discussed can be classified as follows; discrimination, disability rights, social policies, formal implementation problems in achieving legal rights, attitudes of people towards disabled people and religion(Engelliler.biz Platformu, 2021).

2.2 Studies on Visual Disability

Visual impairment is defined by the first Turkish disability related association Altı Nokta as “Conditions in which the visual power (visual acuity or visual field) cannot be reached to a useful level with known methods such as glasses, contact lenses, medication or surgery are called blindness or low vision according to the degree of restriction.”(Altı Nokta, 2021b,my translation). In World Report on Vision 2019, it is stated that “Vision impairment occurs when an eye condition affects the visual system and one or more of its vision functions.”(WHO, 2019:10). On the other hand, with emphasis on the obstacles and barriers caused by social life conditions the following statement is made in the report;“ ‘Disability’ refers to the impairments, limitations and restrictions that a person with an eye condition faces in the course of interacting with her or his environment – physical, social, or attitudinal”(WHO 2019:14). Similarly, on the Altı Nokta association’s website it is written that;

The most important problem experienced by a visually disabled person is not the sightless of the eyes, but society's misconceptions and prejudices about the visually impaired; It is the inadequacy of the opportunities provided to her/him and the inequality of opportunity between her/him and other people(Altı Nokta, 2021b,my translation).

World report on vision 2019 states that, the 2017 Global Burden of Disease Study ranked visual impairment as the third cause of all impairments. Globally, 2.2 billion people have vision impairment (mild, moderate, severe, blindness⁶), almost half of these cases, vision impairment could have been prevented or has yet not to be addressed. In addition, it is estimated that, 11.9 million people worldwide have moderate or severe vision impairment or blindness due to glaucoma, diabetic retinopathy and trachoma that could have been prevented. The visual impairment is often far greater in low and middle income countries, among older people and in women, and in rural and disadvantaged communities(WHO, 2019).

In Turkey, the proportion of the population who cannot see or who have difficulty in seeing even if using glasses or contact lenses is 1.4% (1.3% for men and 1.5% for women), while this rate is 0.6% in the 30-34 age group, it rises to 1.9% in the 50-54 age group(Turkish Statistical Institute [Turkstat], 2011). Among the individuals who applied to authorized hospitals to obtain a disabled health board report and contacted the state for service, the rate of the visually impaired in the distribution by disability groups is 11.1%(General Directorate of Disabled and Elderly Services [EYHGM], 2020).

Contrary to popular belief, any reliable scientific data that the senses such as hearing, smell, and touch are spontaneously more developed in visually impaired individuals than other people could not be found. But, as Enç et al.(cited in Demir & Şen, 2009:155) reveal, the experiences of visually impaired people in interpreting the stimuli they receive through these senses are their advantages. Therefore, educational intervention should be made to provide experiences that encourage the use of

⁶ Mild = visual acuity worse than 6/12 to 6/18 / Moderate = visual acuity worse than 6/18 to 6/60 / Severe = visual acuity worse than 6/60 to 3/60 / Blindness = visual acuity worse than 3/60(WHO 2021)

all senses(Altunay-Arslantekin, 2015; Demir & Şen, 2009; İşlek, 2016). Because this process is not only about the education of the person with visual impairment, it is about gaining independent life skills that will affect the whole quality of life.

The policies determined for the education of the disabled and the actions in this regard of all stakeholders (disabled person, family, educators, school administrators, decision-makers) provide very basic information about the people's attitudes towards disability and the position of the disabled in the society they live in.

Historically, during the Ottoman period, until the 19th century, social support provided to the disabled with the poor was carried out by the Vakıfs, one of the oldest institutions of social solidarity based on philanthropy(Sağlam-Tekir, 2016; Şimşek, 2017). As it is generally believed that disability is a destiny, the state has not developed a policy on the education, rehabilitation and employment of the visually impaired(İçli, 2021).

Public education became more widespread with the effect of the emergence of nation states in the last period of the Ottoman Empire. Studies show that, especially since the end of the 19th century, education activities for the disabled were carried out for the visually, hearing and speech impaired together at schools mostly known as *Sağır-dilsiz ve Âmâ Mektebi* (School for the Deaf-mute and the Blind). Archive researches specifically for these schools provide detailed information about the practices related to education as well as general approach of the period to the disabled people(Balcı, 2013; Demirel, 2013; Yıldırım, 1997). Mustafa Gündüz(2014) who studies the history of education states that;

The lifestyle of the Ottoman society was determined by tradition and Islamic Sharia. In this respect, both the traditional practices of Turkish culture and the provisions preached by Islam were valid for people with different physical and mental defects. On the other hand, it is difficult to talk about educational activities for people with disabilities, either by the state or by private enterprises, until the end of the 19th century(p.6, my translation).

Gündüz also added that “In Ottoman / Turkish society, special attention was given to people with disabilities. With the effect of feeling of pity, almost everyone in the society has helped them”(2014:7, my translation). Additionally, in Altı Nokta’s website its stated that disability is generally believed to be a destiny, so no serious effort was made to prevent it during the Ottoman period(İçli, 2021).

It is necessary to note the developments in the Republic period regarding visual disability as well as disability at large together with the efforts of the educationalist⁷ Mithat Enç, who was visually impaired as a result of an illness at a young age. Enç pioneered the establishment of *Altı Nokta Körler*

⁷ Brief academic history of Mithat Enç: Undergraduate on education and master degree on special education in Columbia University Faculty of Education(1939), Phd from the University of Illinois(1958). The founding director of the Ankara Körler Okulu (School for the Blind 1950-1956), and the Special Education department in Gazi University Education Institute (1952-1955), founding dean of the Faculty of Education of the Middle East Technical University (1958-1960), member of *Milli Eğitim Bakanlığı Talim ve Terbiye Kurulu* (Ministry of National Education Board of Education 1960-1965), founding chair of the Department of Special Education in Ankara University Faculty of Educational Sciences(1965-1977)(Çağlar D. et al.1992, Ankara Üniversitesi 2021, Altı Nokta 2021a, Engelsiz Erişim Derneği 2005).

Eğitim ve Kalkındırma Derneği (Six Dots Education and Development Association for the Blind, my translation), today known as Altı Nokta in 1950 in order to mobilize the civil initiative on the education of the visually impaired and to create a social pressure group (Altı Nokta, 2021a). Enç also promoted the establishment of *Altı Nokta Körler Vakfı* (Six Dots Blind Foundation) in 1972 in Istanbul and *Türkiye Körler Vakfı* (Turkish Foundation for the Blind) in 1974 in Ankara in order to support the education, rehabilitation and employment of the visually impaired. He also supported Makbule Ölçen and a group of other volunteers in their efforts to establish *Zihinsel Yetersiz Çocukları Yetiştirme ve Koruma Vakfı* (Foundation for Raising and Protecting Mentally Handicapped Children, my translation) (Çitil, 2009).

As a result of Enç's efforts to be noticed the drawbacks of approaching the education of the disabled in the context of social help, the schools for the deaf / mute and the blind, which have been working under the Ministry of Health and Social Security since the first years of the Republic, were transferred to the Ministry of National Education in 1951 (Çitil, 2009). Besides, Enç's autobiographical book *Bitmeyen Gece* (1983) as well as many of his studies on special education and educational psychology, which are still cited, make important contributions to the relevant literature⁸.

It can be said that the improvements on disability, which are noted to have gained momentum mostly through personal efforts, progressed in a much more systematic and institutional level after 1980s, and especially with the disability law enacted in 2005. However, above all, today the schooling rate of people with impairment is very low, according to the available statistical data which is not adequate and detailed (Çakıroğlu & Melekoğlu, 2014). For instance, the rate of illiteracy among the visually impaired is 34.9%, while this rate is 12.94% in the total population in Turkey. Including those who are literate but have not attended a school, the rate of visually impaired who are not schooled is 49.4% (Ataman, 2021). The ratio of people with disabilities who receive special education service to total primary and high school students is 3.23%, and approximately half of them are educated in private education or rehabilitation centers instead of regular schools (Ochoa et al., 2017).

It is stated that the legal basis and regulations within the scope of special education services to disabled students in Turkey is quite extensive and they are similar to many leading countries in this regard (Çakıroğlu & Melekoğlu, 2014; Meral & Turnbull, 2014; Ochoa et al., 2017). Correspondingly, as Meral and Turnbull (2014) explain, students' rights to an education begin at birth and continue to age 21, and in special cases, this age limit becomes even longer (p.168). Therefore, in addition to regular education of disabled people, special education expenses are covered by *Milli Eğitim Bakanlığı* (Ministry of National Education) ([MEB], 2012). According to the data from 2015, the expenditures for special education is around \$250 million representing 00.15% of total annual budget of free compulsory elementary and secondary level education (Ochoa et al., 2017:335).

⁸ Some of Mithat Enç's publications: *Görme Özürlüler: Gelişim, Uyum ve Eğitimleri* (1972), *Üstün Beyin Gücü, Gelişim ve Eğitimleri* (1973), *Ruhsağlığı Bilgisi* (1974), *Uzun Çarşının Uluları* (1977), *Özel Eğitime Giriş* (1981, Co-author), *Eğitim Ruhbilimi* (1982), *Bitmeyen Gece* (1983), *Ruhbilim Terimleri Sözlüğü* (1990) (cited in Ç. ağlar D, Özsoy and Bıyıklı 1992).

The adequacy of these expenditures is another matter of discussion but, it is necessary to open a parenthesis about the economic opportunities of the disabled. It is seen that there have been financial improvements for disabled people, which has historically been associated with poverty, especially after the 2000s. Studies show that both direct monetary support (social aid, disabled salary) and indirect financial support (job and retirement opportunities, education, health and transportation services, tax exemptions, etc.) have increased noticeably in the lives of people with disabilities(Ak, 2019; Yılmaz, 2014)

However, although there have been relative improvements, studies reveal that the expected results in practice on education and training of disabled could not be achieved(Bayhan & Sipal, 2011; Çakıroğlu & Melekoğlu, 2014; Çitil, 2009; Demirtaş, 2019; İşlek, 2016; Sakız & Woods, 2014; Şenel, 1998; Şirin, 2019; TOHAD, 2015). It is needed to emphasize that, in studies, not only official practices but also all other parties' (school administrations, teachers, counselors and families) practices and approaches regarding the education and training of the disabled are discussed(Ereş & Canaslan, 2017; Melekoğlu, 2014; Sakız & Woods, 2014; Yılmaz, 2015). The subjects mostly studied in the literature will also indicate which issues exist in this context. The content of the researches is mainly on the curriculum that does not meet the needs, inadequate teaching techniques and a shortage of specialist educators in addition to physical and organizational problems, deficiencies in supervision and limited information both about students with special needs and what they need. When these studies are examined, from the point of view of daily life practices in real life, it is seen that, as Islek(2016) summarizes, "the principles have neither always been adhered to nor implemented completely"(p.18) and "the reason for this does not appear to be clear"(p.62). Therefore, besides identifying the problems in the field of education, it requires research on the causes of implementation problems, as one of the objectives of this thesis.

When the disability literature is reviewed in general terms, it can be stated that studies in academia in Turkey have gained momentum especially in recent years. Emphasizing the importance of an interdisciplinary and historical perspective, as well as the beginning of disability as a field in universities are important developments. In general, studies show that the problems in practice are particularly evident in the context of improving the quality of life of the disabled. In this respect, it would not be wrong to say that the effects of the medical model continue in social life. In addition, it is clear that the issue should be discussed in terms of cultural acceptances, aside from its economic and political dimensions. Therefore, in addition to necessity of detecting and identifying the problems, the need to investigate their causes, that is, their source, becomes even more obvious.

CHAPTER 3

METHODOLOGY

In this study qualitative research method was used to reach knowledge. Thesis findings were based on the experiences of people with disability who attended the study. In this context, I conducted a fieldwork consist of participant observation and in-depth interviews to reach the data.

The road map of the research was not constructed to offer some solutions to the social problems of disability as conclusion, but to investigate the social and cultural causes of the disability issues in the frame of daily living of disabled people and trying to make them visible. Because, when the study was beginning my very first observation I have experienced was the inconsistency between implementation and written statements about disability. Then, the situation of inadaptability between, in simple, the theory and practice was manifesting itself throughout the study. So much so that, I came to conclusion that the activities performed to improve disabled people's living conditions were look like a cure with deficiencies in its diagnosis.

Methodology chapter consists of six sections. In the first one, the questions of the research and the aim of the study in the frame of how they emerged and progressed are explained. In the Strategy and Design of the Research Section, information is given on the strategy of accessing data, the research's framework and content. In the second section, the participant observation process is described in the frame of its space, people and its contribution to the study. In the fourth part, information is given about interviews and interviewees. In the fifth chapter, the analysis and writing stages of the thesis, in which the comprehensive data obtained as a result of the whole study are refined, analyzed and conceptualized, are explained. And, the last section consists of restrictions and limitations of the thesis both within the frame of limitations of the collected data and within the subjects which are excluded in the findings chapters.

3.1 The Aim of The Study and Research Questions

According to the official statistics "total disability proportion in the overall population is 12.29%(SIS, 2002:5). That means 12 out of every 100 people is disabled in Turkey. As my observation, we do not see, physically and metaphorically, disabled people in the society at the rate of

their existence. In this context, the very first question is, where are they, why disabled people are invisible?

After reviewing the written sources on the subject, I have conducted two small scale research projects as the very first research of my study. In the frame of those, I conducted semi-structured and unstructured in-depth group interviews with the families and teachers of intellectually disabled students in a primary school and a special education center in Ankara. In addition, I made short-term observations at school and at the center. The parents did not just speak about their children's disability issues, they talked about their lives both at home and outside. Briefly, they told about their daily life.

In addition to my observation and written sources researched, in the light of what the mothers of disabled children told, my inference was as the following; It looks like there are concerned families and educational opportunities for the disabled, on the other hand there is a disability law based on social model and a substantial money transfer from the state to disability issues. But, it does not work in the context of daily life quality of the disabled, or with the best scenario, it does not work effectively. So other questions of the research emerged; why the system does not work effectively? Why did mothers say "we are not seen" and "those made are useless" despite all seems to be done to improve the quality of life of the disabled? There should be some fundamental reasons of this situation. What are they?

Disabled people, their families, those people in their schools, managers at workplaces, people in the streets and even the practitioners of the laws and state apparatus are all members of the same society. Therefore, I argue that, one of the important part of those fundamental reasons should be the society's cultural and social understanding and perception of disability. It is this understanding and perception is the basis of people's reactions and behaviors against disability both in one-to-one contacts and in the conceptual context. In other words, it is basically social and cultural factors that determine the approach of people living in the same society to disability. To illustrate more concretely, it is fundamentally common social and cultural factors that shape the approach of the rule makers to the subject, the teaching methods and motivations of teachers, the approach of managers and coworkers in workplaces, the attitude of the person on the street towards the disabled, the family's decisions regarding the life of the disabled family member, and even the perception of the disabled person about disability. Therefore, another question, which essentially intertwined with each other is, what are the fundamental social and cultural perception and understandings of disability in Turkey?

It is obvious that it is not possible to reach all social and cultural factors of the whole country's perception and approach of disability in a master thesis. Therefore, my arguments and research field determined the scope of the study. My first argument was that, unproductive results are being taken from those made on disability issues. My second argument was that, one of the main reasons for this inefficiency is the social approaches and cultural perspective that shape people's practices related disability issues. In this context, my other argument was that while the ratio of disabled people to the population is so high, there should be a link between the invisibility of

disability and these approaches and perspective. Hence, the society's cultural perspective and social approaches and perceptions of disability in the context of being invisible were searched through the experiences of the research's participants.

Conducting the research in line with the participants would also help to transfer disabled people's experience to the academy. This is important for two reasons. Firstly, the disability is one of the very least studied fields in academy in Turkey. Essentially, that situation can be considered as a part of the invisibility of disability. Secondly, there is a need of anthropological view to the issue which give importance to daily life experiences lived.

In sum, the first aim of the study is searching the fundamental social and cultural perspectives, understandings and approaches of the society that are claimed to cause inefficient practices in disability-related issues in the context of invisibility based on daily life experiences. The second aim of the thesis is to contribute to the transfer of the experiences of the disabled people to academia and society. The disability is studied very few in social sciences and particularly in anthropology in Turkey. In this sense, it was hoped that the research will contribute to both academia and the society.

3.2 Strategy and Design of The Research

The research is designed to reach the answers of the thesis questions from daily living experiences of disabled people. The key issues and general frame of the study were determined before the field study. However, the research was mainly planned without delimitation as possible on being able to recognize and understand the participants' experiences lived, and thus to be able to grasp social reality. For this purpose, participant observation and in-depth interview techniques were chosen as the fieldwork.

The experiences of people with disabilities are emphasized when designing the research because there is a huge cultural gap to integrate the experiences of disabled people into society. In fact, it is not only an observation of mine. This is also the view of a mother with a mentally disabled child who explains why families do not accept their child's disability by saying, "Because they don't know what the disability is. We didn't know it before our children either." It is also the suggestion of a well-known feminist philosopher with a disabling chronic disease Susan Wendell(2006);

There is a danger of sentimentalizing disabled people's knowledge and abilities and keeping us "other" by doing so. We need to bring this knowledge into the culture and to transform the culture and society so that everyone can receive and make use of it, so that it can be fully integrated, along with disabled people, into a shared social life(p.254).

Therefore, the experiences of the participants determined as the core data source of the research.

Disability is an extremely wide, complex and overlapping subject. Experiences in social life may differ according to the category of disability. In this context, conducting the study by a particular disability category is a determining factor in understanding the society and obtaining reliable

information. Therefore, at first, I decided to continue my research based on the experiences of people with Down syndrome, and in this context, I did the small field research I mentioned above. In the next phase of the research, I needed to conduct in-depth interviews with people with Down's syndrome. However, at this stage of the study, new regulations have come into effect by Ethical Committee for Human Research of Middle East Technical University [METU]. According to the new regulation, it was not clear whether the interviews with the mentally disabled would be approved by the Committee. In this case, I have changed the research field with people with Down's syndrome to visually disabled people.

Changing the focus group after completing preliminary study of the research was not easy and quick. However, the preliminary study added a lot in the formation phase of research questions. Besides, it was determinant in terms of seeing the common issues in the state of being physically or intellectually disabled in society. Therefore, the preliminary study process contributed to the formation of some themes such as the inefficiency of the work done on disability issues, as well as the lack of knowledge of the society about disability and the invisibility of the disabled. Through this process, I made clear not only what to research, but also where to look for it.

In addition, after preliminary field study I have come to conclusion that, the society's cultural and social perception of disability is also internalized by the disabled people and their families as they are also a part of the society. They may have form their lives in accordance and acceptance of this perception. Therefore, since they will be the most aware part of this perception of society, I wanted to try to find my questions' answers from them.

The research was planned to detect, follow, analyze and convey daily life experiences of participants in the frame of the study's questions. Therefore, concepts and perspectives which most discussed and analyzed in mainstream disability studies were not the beginning point of the research. That is, I did not made observations in the context of some particular themes or concepts which I had determined from literature in advance. While spending time with them during the participant observation process, I tried to reach the concepts and approaches that are most relevant to their daily lives.

Likewise, in in-depth interviews, the perceptions, the concepts and approaches that I have been familiar with by the literature of disability studies specifically were not given to participants. They were asked in detail about their daily life experiences in the frame of social life, family life, education, working life and state related issues. The purpose of this was to bring out the concepts and themes that are decisive and significant to the participants in their daily life. They were also asked questions about their comments and opinions of their experiences. Thus, I would be able to understand the general perspective and approach of the society through the participants who are part of the society.

In addition, participants were asked whether other persons with different types of disabilities experienced situations similar to their own. The objective to that is to see if what is stated by them can

be attributed to the general understanding of society. Because, the basis of the participants' perspective and approach to disabilities that they did not personally experience would be a reflection of the society and culture they were in.

The theme of invisibility was the only exception of this which asked directly to participants. Because from the very beginning it was my argument that disability is invisible in society and that there is a direct correlation between this invisibility and unproductive outcomes related to disability issues. But the argument was only a beginning. Hence, questioning my argument was included the framework of the research. In other words, the participants were asked whether disability was invisible to them and what invisibility meant for them in social life. They were also asked about their experiences and opinions on what has been done with disability issues, in order to question whether what was done was really inefficient. And, analysis were made in line with these answers in addition to my observations.

3.3 Participant Observation

I was a volunteer teacher between December 2017 to September 2018 at ODED, a non-profit association in Ankara. ODED supports people with disabilities who are studying or graduated in high school to prepare for university entrance exam. I was aware of ODED through the METU Without Barriers community. Then, I attended to an introductory meeting they are looking for volunteer teachers in ODED. I met with students, other volunteers and managers of the association. We determined the lessons and the appropriate hours both to me and the students, so I started teaching there.

ODED was chosen for the participant observation because it is an environment where I can spend time with visually disabled people and can observe in a part of their daily lives. In addition, preparing for the university entrance exam has been experienced for a period in almost every part of the society who desire and can continue education after high school. In a sense, it is a process experienced by all segments of the society. However, it is also a process that can cause distinctive different results for different segments of the society. Therefore, observing the experiences of people with disabilities who came together for a goal that I am familiar with enabled me to recognize the distinctive features of society's cultural and social approach to disability.

The study is continued with the experiences of visually impaired people since February 2018. Therefore, it can be said that, the participant observation process of the fieldwork lasted for about 8 months from February 2018 to September 2018. I was teaching philosophy group lessons for one day every week, mostly on Tuesday, for about 3 to 5 hours a day. Sometimes I was there for two or rarely three days a week when other volunteer teachers were unable to attend classes or when students needed additional lessons. Besides, I also participated in some events such as picnics, shopping,

birthday parties or some other celebrations and meetings. Everybody attending the courses and also the directors of the association were aware of my study and research.

The general framework of the research was formed before participant observation began. In this sense, some issues that I needed to pay particular attention to, more precisely the questions I was looking for answers to, and some inferences or arguments in need of confirmation were evident in my mind. However, my goal of the participant observation process was to understand to be able to intellectualize. That is, my goal can be explained with Bernard(2006)'s words as;

Participant observation involves immersing yourself in a culture and learning to remove yourself every day from that immersion so you can intellectualize what you've seen and heard, put it into perspective, and write about it convincingly. When it's done right, participant observation turns fieldworkers into instruments of data collection and data analysis(p.344).

During my presence there, 8 visually impaired people, three women and five men, aged between 18 to 22, were attending university preparation courses at ODED. Four of them were completely blind which they were calling just "total"(totally) to this situation. Others have some different severe eye and seeing problems. In addition, one of them had also epilepsy, another one also had a kidney transplant. Before I became a volunteer teacher at ODED, I did not have direct contact or personal relationships with visually impaired people. This situation allowed me to see their daily life from outside and from a larger window. At the same time, being in close contact with them as their volunteer teacher over time made me understand them as possible as it can be.

The Association was in Kızılay, Ankara at an apartment consisting of three rooms used as classrooms, a seminar and meeting room, an executive room, a kitchen and a bathroom. It was more like an intimate home environment than a formal education place. During this period, I had chance to spend time with visually impaired young people, their parents or other relatives, volunteer teachers most of whom were university students, an association administrator, and rarely other association managers. In addition to these, I had the opportunity to meet and spend time with former students as they often came to visit the association.

The classes at ODED contributed a lot to the research. Being in close contact with visually disabled young people as a teacher made me understand the issues that were decisive for them. It also allowed me to distinguish whether these problems were due to social acceptance or personal reasons. So I caught some clues of the society's perspectives on the relevant issue. The classes also made me realize the similarities and differences of visually impaired people with other people in the context of their daily life practices.

No matter how much I read the literature, I understood what was really going on in the fieldwork. Similarly, when I spent time with them, I realized how important the seemingly small details are in the lives of visually impaired young people. For instance, I noticed that they divide people into "us" and "them", as visually impaired and non-visually impaired in social life. Such that, most of them say *kör* (blind) to each other when joking, but if someone who is sighted uses this word,

most of them perceive it as an insult. On the other hand, some are angry with those who perceive using the word *kör* as an insult because for them it's just a 'situation', there is no need to attribute a worthlessness to blindness. Likewise, I noticed that being dependent on a family member in their daily life has become an ordinary thing, but they also admire the visually impaired who can live on their own.

I had the opportunity to chat with some family members of the visually disabled students and some of former students during breaks or in free times. When subject of those conversations came to my study those inevitably became unstructured group interviews. I added the information I received from these speeches to my field notes. These field notes also contributed to my findings and analysis.

I also spent time with students outside of the association's place. It enabled me to observe people's reactions and behaviors towards the visually disabled on the street when we went shopping or picnicking. Thus, I experienced some of the issues that were decisive for the participants with them.

Being involved in the daily lives of visually impaired young people at an important turning point in their lives, provided me to understand them and their experiences as possible as it can be. Additionally, I observed their interactions with each other, with their families, with sighted volunteer teachers, friends, administrators and people on the street. I tried to understand how they position themselves in society, how they perceive social life compared to themselves. Therefore, I tried to catch the cultural perspective and social approaches that are not noticed in the routine of daily life but are determinant for them.

3.4 Interviews

The interviews throughout the study were conducted in forms of unstructured and semi-structured in-depth interactions. The narratives referenced to the analyzes in the findings chapter are based on semi-structured in-depth interviews conducted with visually disabled young people detailed below. In addition to this, expert interviews were also conducted. Besides, due to the nature of the participant observation, which can be categorized as unstructured interviews and group interviews also contributed to the study. Because;

Unstructured interviews are based on a clear plan that you keep constantly in mind, but are also characterized by a minimum of control over the people's responses. The idea is to get people to open up and let them express themselves in their own terms, and at their own pace (Bernard 2006:211).

Semi-structured open-ended in-depth interviews were held with 15 visually impaired people between ages of 18-23 living in Ankara and studying at a university or preparing for the university entrance exam. All interviewees were informed about the thesis subject matter, the aim and scope of the study at the beginning of each interview. Six of the interviewees were continuing courses in ODED. Others were former ODED students and their friends who wanted to attend the research.

Instead of the real names of the interviewees, pseudonyms were used in the thesis to ensure confidentiality and respect privacy. Table 2 summarized the profile of participants of in-depth interviews.

Table 2: Profile of the In-depth Interview Participants

Participants*	Age	Gender	Degree of sight**	Visually impaired since	Education	Occupation
Alp	18	male	Low vision / night-blind	birth	High school student	
Murat	19	male	Blind / low vision	1 month old	High school student	
Yeşim	19	female	blind	birth	High school student	
Esra	20	female	blind	birth	High school student	
Rıdvan	19	male	blind	birth	High school	
Mustafa	21	male	blind	birth	High school	
Mehmet	22	male	blind	birth	High school	
Elif	19	female	low vision	birth	University student	
Neşe	20	female	low vision	7 years old	University student	
Aydan	21	female	blind /low vision	birth	University student	
Erkan	22	male	low vision	birth	University student	
Melek	21	female	low vision	birth	University student	government employee
Şule	22	female	blind	birth	University student	government employee
Semiha	22	female	blind	1 month old	University student	government employee
Meltem	23	female	low vision	6 years old	University student	government employee

* Pseudonyms of the participants

** Blind: fully functional visual impairment or only light perception

Low vision: Some degree of functional vision impairment, at least 40 percent (reported by the interviewee based on Disabled Health Board reports given by authorized hospitals).

Night blind: Inability to see at night or in low-light conditions

The participants were all single and living with their families. They reported that, one of them was living in their own squatter settlement (gecekondu), two of them were tenants, four of them were living in houses where their families continued to pay mortgage, and eight of them were living in their own houses. 13 of them reported that they have their own room in the house and two of them reported that they were sharing their rooms with one sibling. All stated that their family incomes were higher than the minimum wage. 13 of the participants defined their family income as average, one of them as lower than average and one of them as above average.

In semi-structured in-depth interviews, the questionnaire was consist of 53 open-ended questions. In addition, it also included sub-questions of the relevant question for situations that must be asked according to the answer given or require approval of the answer given. The topics of questions were personal information, everyday life, education, family and relatives, working life, social life, disability perception and definition, the state, non-governmental organizations and the society. Due to complexity and multiplicity of the themes, large number of questions, and most of the participants' willingness to express themselves in detail with their personal history base the interviews lasted an average of 120 minutes, ranging from 80 minutes to 180 minutes. Pilot interview was

conducted for clarifying questions and for determining whether there were questions that participants may be uncomfortable with and to determine the possible timing of the interview. All semi-structured in-depth interviews were held face to face in one of the classrooms at ODED in between March to June 2018. All of them were recorded via the mobile phone voice recording application with the permission of the interviewees. After each interview, the audio recording was decoded and the transcriptions of each interview were examined. By doing so, prominent issues for the interviewee, and if any, the experiences similar or different to previous interviewees were determined.

In addition, two expert interviews were also conducted. One of them was with the vice president of the association as a semi-structured open-ended in-depth interview. He was 28 years old, visually impaired, university educated and working. He stated that he came to the association as a student to prepare for the university exam, and that he never lost his connection with the association and the students after that. Other expert interview was unstructured interactions with a 64-year-old, sighted, half-volunteer employee who has been managing the association for about five years. During my time at ODED, I observed that these two people had deep knowledge about the lives of visually impaired young people. For this reason, expert interviews were conducted in the frame of the data I obtained from the participants.

3.5 Writing Stage and Data Analyses

As explained above, the aim of the study is to reach the fundamental social and cultural perspectives, understandings and approaches that are claimed to cause inefficient practices in disability-related issues. But disability itself, relevant social and cultural approaches and even the daily life experiences of the participants are very wide, multi-layered and multi-faceted areas. In addition, when the fieldwork and source readings were completed and I came to the writing stage of the research, I had a very large, complicated and complex data corpus in my hand. Ultimately, the study had achieved its purpose, but so much data and conclusions needed to be written down in an understandable and clear way, just as they should be made clear in my mind. To put it in another way, I had reached the answers that were the purpose of my research before the writing stage of the thesis, but the data had to be simplified, operationalized and some of the findings needed to be conceptualized.

Therefore, in the findings chapters of the thesis, the things that seem ordinary or simple in daily life were taken as the starting point and the subjects as well as themes were analyzed within the framework of these from a broader context. In order to do this, I first identified indicative things as clues, like abstract concepts such as pity, repetitively mentioned expressions as “*yapamaz*”(cannot do), or concrete materials, such as the white cane, and so on. These were indicative clues and needed

to be analyzed because they were constantly mentioned in different contexts both in conversations and in semi-structured in-depth interviews.

Also, although these clues may seem like simple and ordinary elements of everyday life, they made me understand the issue from a broad perspective when I followed them. To follow them, I grouped all interview transcripts according to the relevant issue by re-scanning, rereading, and listening to audio recordings again if needed. I also created tables of relevant subject. Those tables were a way to list every participants' narratives. Thus, I determined the participant experiences that were common and different for each subject. In addition, I scanned my field notes, research and written source notes on the basis of the relevant issue. When necessary, I made deeper search for written sources and literature on the subject.

Afterwards, I examined the reflection of these clues on social behaviors and approaches through the experiences of the participants on different topics. The concepts and terms are like buttons that shed light to issues that are related to participants. Namely, after identifying them, I reexamined these clues and concepts in the unity of everyday life, but in the context of social life, family, education, working life and the state related issues. Thus, the data was operationalized and refined, some findings were conceptualized, and the research result emerged.

3.6 Restrictions and Limitations

The research focused on the social and cultural reasons of the subject through daily life practices. Due to the limitations of the thesis, the state related subjects have been only examined when daily life practices require it. In other words, the state was processed when needed in order to understand the general approach of the society on disability through the practitioners of the state apparatus, not through focusing on social policies of the government. Likewise, the economy is an integral part of everyday life. In this context, themes related to economics were included in the thesis but the effect of neoliberal economic order on disability implementation have not been directly examined as a theme due to limitations of the research.

Throughout the study, I have frequently encountered statements of the abuse or misused of social emotional sensitivity regarding disability in different contexts by the participants. I believe that the abuse of disability is an issue that needs to be searched on its own in the frame of economy, the state, the family and also the society. Therefore, the subject of misused or abuse has been excluded from the study within the limits of the thesis.

The disability, as a term, comprises a wide range of concepts in disability studies. Therefore, it is needed to remind that the concepts in the thesis are limited due to experiences of the group of people that I studied with. Even so, some of the frequently discussed concepts in the mainstream disability studies like 'stigma' have also been added and analyzed if they had been surfaced during the

fieldwork. But, although some concepts were used frequently by the participants as expressions, they were not directly analyzed in the findings chapter. Because, I did not have enough data what exactly those concepts imply to the participants.

The most prominent of these was the ‘normal’ or ‘normality’ or ‘normalcy’, as can be seen in the literature review chapter. According to my fieldwork of the study, those without disabilities were expressed as *normaller*(normals) by the participants. But, there is not an exact duality like normal and abnormal in their usage of the word as it was mostly discussed in the mainstream disability studies. In addition, most of the participants stated that it is practical to use it when asked them why using the word normal to define not disabled people. Therefore, at one point it is not clear whether the word normal is used to specify something alleged perfect or it is just a practical simple and quick usage in daily life. However, this expression of normal has become so internalized that it is adapted to any situation. To me, although needed to be searched in-depth, it seems that there is not a constituted category of “normal” in the society but problematic of self-sufficiency. That is, it looks like, stereotyping disabled people, for example, as incapable derives its source from the assumption that they are not self-sufficient people, not from comparing them to an accepted category of the normal. Nevertheless, I think it is necessary to investigate why the word normal has been so internalized. The concepts of “normal” or “normalcy” or “normality” should be studied on their own in historical and cultural contexts by comparing them with the societies in which the social model flourished. Therefore, this concept was not included in the findings sections of the thesis.

CHAPTER 4

HELP-ONLY APPROACH

Disability is a socially constructed phenomenon. How the society reacts to a disabled person is an indicator of how disability is perceived and understood by the society. The life quality of people with disabilities has a direct relation with that social perception and understanding of disability. Because, what is performed about disability issues by all the social institutions, from the disabled and their families to their close circles, from the people on the street to the state, will be formed within the framework of this perception and understanding. It is needed to highlight here that all these activities also reproduce the same perception and understanding again like a vicious circle.

People with disabilities are seen as people who always need help in the society. Because, although the interview of the research was not prepared for trying to understand whether people help visually disabled persons or not, most of the answers revolved around the concept of help. That is, the help was one of the most pronounced word related with different kinds of issues by the participants throughout the study. That makes me think that, it is ordinary to help a visually disabled person in the society. In so much so that, according to the interviewees, not getting help was out of question at the streets, or at school, or in family or even by the government. This situation has been so internalized that the problem for the participants was lack of knowledge in the society about how should be performed the help. In addition, through the experiences told by the participants of the study, it can be said that receiving help is almost a "god-given right" of visually disabled as a cultural perception of the society.

One of the interview questions and its answers can be given for a concrete example about the subject to reveal the situation. The question was "Outside, on the street, on the bus, on the subway, etc. how are people behaving to you?" Answers of that question were more or less almost the same as; "If people realize that I am visually impaired, they always want to help, with rare exceptions."

At first glance, it can be thought that this approach of the society is not a problem as it makes life easier for the visually disabled people, in contrast, rather a situation that should be grateful. As a matter of fact, it should be stated here that, it has made a very important contribution to overcoming daily and instant troubles of disabled people. However, I have noticed that the participants mostly did not give positive comments on this subject, on the contrary, they focused more on the mistakes people make while helping. For instance Mustafa said that;

Because people are ignorant, they don't know how to treat to us. I experienced the same today, while walking on yellow line⁹, a man crashed into me and did not apologize. People should change their standpoint of visually disabled, seminars can be given to change their attitudes to us. For example, we have a guiding order, we need to hold their arms and they have to walk behind us, but they grasp our arms, they disturb our balance. People help but don't know how to help.

We have been focused a lot on this topic both in interviews and in daily conversations, because participants have consistently had similar expressions about the mistakes people make while helping out. As the talks deepened, it became apparent that the existing state of helping the disabled in the society derives largely from the perception that “the disabled cannot do”(engelli yapamaz). The answers to the questions related to society’s understanding and perception of the disabled concretely reveal the situation, as can be seen in the below Table 3.

Table 3: The Society’s Understanding and Perception of the Disabled

	What would be your answer if asked “what do we understand when saying 'disabled' in our society, please answer with a word, concept or analogy”?
Alp	I think, as a person in need of someone else, our nation also thinks so.
Murat	Crippled, incomplete I mean not solid, rotten.
Yeşim	I think our nation understands someone who needs help, who has broken her ties with life, that is, in a pitiful state.
Esra	In general they feel pity to us, in fact not only to visually disabled but to all disabled people
Rıdvan	They see us as someone other than the normal human. They see us as if we are higher or lower than them, they usually see us low.
Mustafa	They say cripple, he cannot do anything, he cannot handle himself, should not try to do something in vain, such perceptions are formed in the society. If they actually see what we can do ...
Mehmet	Someone who is unable to work, I guess
Elif	She cannot see, hear, speak, or walk. As far as I know, these are understood. She doesn't see things, so she cannot make things.
Neşe	A person who cannot manage herself, cannot do anything by herself
Aydan	The society perceives as someone who cannot do much
Erkan	In society, I guess, an individual who cannot do things alone, that is, someone who needs someone / cannot be an individual, is just a living being.
Melek	Inadequate or handicapped, incomplete (person)
Şule	Insufficient, unable to do things, so disability means unable to do things(in the society)
Semiha	The disabled cannot do anything, should stay on the sidelines, thus no cost to us
Meltem	It is perceived directly as an ineffective object, disabled cannot do anything, something passive

As can be seen in the answers given to the question, the participants stated the perception of “the disabled cannot do”(yapamaz) as the shortest description of people's thoughts about disabled people. Therefore, when the general judgment is “the disabled cannot do”, helping the disabled becomes a natural form of behavior. In other saying, as stated at the beginning of this section, getting help seemed almost a natural right for most of the participants.

⁹ Since tactile paths for the use of the visually impaired appear as a yellow line, they are popularly called the yellow line(sarı çizgi) or guidance paths(rehber yollar).

Jenny Morris(1991) who is a disabled feminist writer describes the situation of help in this context as;

When we interact with non-disabled world it isn't just staring and people's feeling about our physical differences that we have to deal with. We also have to deal with the issue of help- the help which non-disabled people often offer us, and the help which some of us need in going about our daily lives-(p:24).

It is not wrong to say that, helping each other is the act of being alive, a need of social life for both the receiver and also to the giver as Semiha said;"I often come across to those who want to help (when walking). Humanity is a sadaka(alms) after all, I allow (them to help) for that, I can do it (things offered to help) in fact, I mean, I do not push those who make humanity, at least we talk together..." But, the inconvenience arises when the help is considered as a regular form of interaction with disable people, and became an issue that is needed to be dealt with. Semiha expressed her discomfort on this issue as follows:

As my eyes do not see, you know, people usually think that everything consists of seeing, they limit themselves to this, they don't know... They only communicate with me for helping, they don't have a chat with me. Those who sighted are immediately become intimate, as if they have been meeting for years. But when it comes to a disabled, there is not anything more than "let me help the disabled.

Burcu(2006) states that, "the main emphasis on labeling disabled people is not on the physical characteristics of the individual, but on the clear or embedded meanings that arise in the individual's interactions with these characteristics in their daily lives"(p.71,my translation). According to The How The Society Perceives People with Disabilities(2008) research, that reported based on non-disabled people that, a significant portion of the society perceives disability as need for help, in addition, something from God, bad luck, difficulty, and considers disabled people as pitiful, weak, inadequate by focusing on the emotional consequences of disability on people(ÖZİDA, 2009).

Similarly, based on the statements of the participants, the behavior of helping the disabled in the society emerges in the context of pity for the person who is thought to be in need, as well. In this form, the help is not always established within the frame of recipients' demands, but helper's stereotypes or prejudices. Therefore, it raises the case of a neediness. Elif's told also summarizes the other participants' considerations of the issue;

I have met people who looked at me with pity. So they pity me. If people saw me as an ordinary person, they would not have pity. That is the help, yes, but by seeing imperfections, seeing as an incomplete, not for humanity or kindness but as the result of pitying.

But, how can it be possible demanding help but asking not pitying at the same time? Murat answered this question as;"As it is from the heart, not with such humiliation, as it is sincere, but as it is from within... How can I say... I mean, not with pity, but with a smiling and talking like "come and let me help you brother". If it's done with pity, better not done at all."

Herein it is essential to clarify the difference between to help(yardım etmek) and to support(destek olmak). In Turkish dictionary, help(yardım) is defined as;“Using her/his own power and opportunities for the sake of someone else, charity-aid, the contribution and support to make the works more effective and efficient”(TDK, 2019, my translation). And, to support(destek) is written as;“Provide power, assist”(TDK, 2019, my translation). Therefore, while supporting is to share power among equals, helping is to bestow power. This situation naturally creates hierarchy between the recipient and the giver of the help. Şule, a psychological counseling student and disability activist, explained the situation as follows;

The point of view of people, that is, when I go from place to place, there are no problem in places I know, I have memorized the numbers of poles or trees, their places and so on. But, people hold my arm, some directly hold without saying anything. Some asks, “Where do you want to go sister?”, however I'm saying that I can go on my own, they still shout behind me as “but sister, sister, I can help!”. People constantly interfere to my private space, I mean, there is seriously an unconsciousness about respecting independent life. I mean, I think it would be because of lack of consciousness. And, it may also be this, if the person offers help without seeking any request or need, the person sees the other one as incapable, and s/he tries to feel superior over this weakness, I think this subconsciously is like this.

This situation, namely the hierarchy that was formed during the help, was actually a position that the participants were very uncomfortable with and therefore frequently mentioned throughout the study. Another factor that they emphasized in the context of this issue was that, the way of life of the disabled people was not known by the people in general. Şule continued as follows;

I think this attitude can be removed with a real empathy. When we say real empathy, empathy means, in general understanding, putting ourselves in the place of the other, but actually it is not, but, trying to understand the other person on her terms. What are my conditions, for instance, I live as a blind person, I have sustained my life accordingly, I have reached my age and there are certain techniques, I have methods, I have developed myself and so on. But, the other person doesn't know this. This is where it comes to selfishness, in fact, people should understand me based on me, not themselves. Yes, what I mean by selfishness is that, they always think of themselves, they start from themselves. It leads to ignoring that there are other realities and other people in life.

To summarize the statements of the participants, the help provided to disabled people manifests mostly in the spiral of pitying, ignorance of their way of life, disrespect of their privacy and the hierarchy. In this case, it is difficult to say that what is being done is support, but it would not be wrong to say that it separates those with disabilities from the whole of society. At this point, the help, which is expected to have positive results, produces negative consequences and becomes a contradiction in the life of the disabled people. Because the case is not only how people behave to the disabled on the street, but how the society's entrenched perception of “the disabled cannot do” directs almost all activities related to disability issues. Therefore, this perception is put into practice by people from every segment of the society with the thought of there is nothing that can be done but help.

I reached the above-mentioned conclusion on the help-based understanding and practices to the disabled, from obtained data by the in-depth interviews as well as gained experiences and

observations in the process of participating in the daily lives of the young visually impaired people. In the light of the research findings, the characteristics of the understanding and practices based on helping the disabled in society can be listed as follows;

- has deep-rooted social and cultural foundations
- internalized by the public as a natural right of the disabled,
- originates from the assumption that the disabled person cannot in any case
- based on the social understanding that there is nothing that can be done but to help.
- common in society
- practiced by different segments of society (people with disabilities, their families, people in school and education services, government officials, people on the street)
- provides temporary convenience in daily life,
- leaves no room for permanent improvements in everyday life
- prevents the improvement of quality of life

To give brief concrete examples of the subject discussed in detail in the following sections; The reflections of this situation on social life, that is, on practice, are manifested in almost every disability-related activity (or inactivity) by the people who constitutes the society. In other words, the understanding and its practices based on helping the disabled, makes social awareness creation meaningless and the accessibility loses its importance in the society. More importantly, this perspective is also accepted and applied by disabled people and their families as they are members of the society. Therefore, for example, independent life skills training is considered as a kind of waste of time.

There are some concepts in the disability studies literature that remind of this help-based perspective of the society. For example, Carlton(2000) examines the social position of the disabled in terms of human rights and explains the attitude towards the disabled with the “disability oppression”. Carlton stresses that, the lives of people with disabilities are considered as “less”, because their bodies or minds are considered as “less”. According to him, the ideology of paternalism, which is the source of pity and shame, is reflected in the lives of the disabled as oppression. He characterizes the behavior that disabled people are exposed to, such as being treated as children or being seen as poor in need of donations, as paternalism in the context of disability. Carlton emphasis that; “It is most of all, however, the assumption that people with disabilities are intrinsically inferior and unable to take responsibility for their own lives”(p.53).

Some of the findings obtained in the research can be re-read based on “disability oppression”, which can be easily verified, for example, in the context of pity or underestimation. However, it is not an explanation of some other practices that are structured on help-based understanding of the society. For example, seeing the act of helping to disabled people almost as a god-given right to such a wide extent in society cannot be explained only as a disability oppression. Because, there is a complex structure of agents from different cultural and social elements in help-based approaches and practices.

Those concepts may refer some of these inputs, but it will be incomplete if the situation is only examined by paternalism or disability oppression.

Another concept that comes to mind in the frame of the findings is “ableism”. According to ableism, people with disabilities are often seen as a burden, a handicap, a drain on the system, who do not making a civic contribution to society, because ableist belief values certain things as their appropriateness and types of contribution. Hence ableism does not consider people with disabilities as “properly human”. Because, to ableist understanding, disability somehow means a condition of lack of status and value(Campbell, 2012).

The participants also stated that they were not perceived as a full human and that they were seen as "half". However, it should be noted that the origin of this attitude in society cannot be found only in the context of contribution to production, which is frequently examined in disability studies of societies experiencing industrialization in the 19th century(Davis, 2013; Scheer & Groce, 1988; Stiker, 2002). However, according to the findings of the field study, it can be found immediately in the context of "self-sufficiency". In other words, according to experiences of the participants, disability is not perceived as a situation that should be "cured or indeed eliminated"(Campbell, 2012:213) because disability is considered as a burden on the system. But rather, disability is perceived in the society as a kind of accepted destiny of those who cannot be self-sufficient as the result of their bodily or mentally disorder and as a condition that should be accepted as it is.

There may be some similarities with some concepts in the disability literature, such as “disability oppression” and “ableism” discussed above, with the help-based perspective of the society analyzed here. However, it is worth noting that, they are separated on some important issues within the framework of the social and cultural resources of this perspective and its reflection on practical life. In addition, disabled people may be exposed to some common attitudes in different societies and geographies in some respects. But, cultural differences, as well as socioeconomic and political elements, are decisive in a society's approach to disability and its resulting practices.

This help-based perspective to the disabled is a social approach with cultural characteristics in itself. The behavior of helping the disabled is so internalized and widespread by people from different segments of society, that it provides convenience from time to time in the daily lives of the disabled, but also causes an obstacle to the disabled due to the acceptance that there can be nothing to do but help. At this point, it was necessary to express the approach with a concept that includes these basic features. From this point of view, there was a need for an inclusive conceptualization of the common practices of different segments of the society related to disability, taking into account common social and cultural perspectives, and thus allowing the analysis of the data obtained in this study. Because, the concepts in the existing disability studies literature, which I had the opportunity to review, were not enough to meet this need.

The conceptualization offered by the thesis to distinguish the act of helping, which facilitates daily life of the disabled to some extent, from the construction of disabled as needy and invisible

through the above mentioned help-based understanding and practices is the “help-only approach”(sadece-yardım yaklaşımı).

The help-only approach refers to the social understanding which creates any kind of activities that just provides impermanent and inadequate conveniences to persons with disabilities. It does not contribute to the functionality of the person being helped, as it is based on the understanding that functionality would not be possible. In other word, it involves a prejudice that accepts disabled as the person who cannot do in all cases. That is, the main motivation of help-only approach in the society is based on the presumption of *engelli yapamaz*(disabled people cannot do). Such a presumption does not leave room for the option that daily life can be maintained by different training techniques apart from the mainstream education methods, or, the issue of regulation of environmental factors or the vital importance of accessibility cannot be understood by the society, or, even formal theoretical rules from the top are written on a right-based basis, effective results for the disabled cannot be obtained when it approaches to the implementation.

In the following subsections, the cultural and social origins of the help-only approach, and its practices in the daily lives of persons with disabilities were examined within the framework of family relations and its effects, life on the street, education life, workplaces, and the state implementations.

4.1 Family: Oppressive-protectionist Help

In today's living conditions getting help is almost a must-have thing for performing activities of daily living of people with visual disability. The content of help depends on the level of impairment, following that, whether the techniques for fulfilling daily living skills and independent movement skills are trained or not, and also problems of accessibility as the result of environmental barriers. The experiences of the participants on this issue reveal that the skills training are thrown aside out of focus in general.

Daily life skills are personal self-care activities that should be performed regularly to maintain a reasonable level of health and safety. Some of them are eating and drinking skills, personal hygiene, housekeeping, culinary skills, clothing care and so on. The independent movement skills allow a person to move from place to place with mobility and orientation skills. The orientation and mobility skills are two dimensions of independent movement. “Orientation skills include an awareness of space and understanding the situation of the body within it, mobility skills cover moving safely without facing any danger”(Materialist & Gray, cited in Altunay-Arslantekin, 2015:37).

Independent movement training is the techniques that provide the visually impaired the ability to determine the direction and act with the least or without help. It contains walking, white cane techniques, finding the source of the sound, using the sense of smell and so on. Both daily living and independent movement skills training are essential for visually disabled people to live safely and

independently (Altı Nokta Körler Vakfı, 2016; Körleri Eğitim ve Kalkındırma Derneği, 2021; Köşeler, 2021; Ministry of National Education [MEB], 2008). It is needed to note here that, these themes are described here, within the limits of the study, as they are used in everyday life, and as general as possible based on my observations and relevant written sources. The types, details and techniques of daily life skills and independent movement skills training are the subject of another study. However, the inadequacy of these trainings, the social reasons for this and the consequences in the social life of disabled individuals are the subjects of this research.

Some of the participants stated that they learned daily life skills from their families. Many of them said that they met the personal needs of daily life "somehow". Even though some of those did not dwell much on this, what they meant was that, they handling their daily lives with the help of their families. And, independent movement skills are almost out of question until an unavoidable requirement actually arises.

Since the direct interview with the families was not the part of this research, the participants told enabled me to obtain very comprehensive data. Elif mentioned about visually disabled people who never go out or only being go out with their family and said that;

They do not go out because they are afraid. They should be reintroduced to society by talking, training and practicing with them. Their families also do not allow them to go out alone for fear of what if anything will happen to them. Actually they are doing evil, maybe if those families are shown more examples they would be convinced... It was very difficult for me to go to school without my elder sister, whether it be encouragement or study, in every aspect.

It is understood that, the fear that any bad thing would happen to visually impaired people, or what I might call avoidance of any assumed danger, predominates. The narrative of Şule, who has similar experiences with other participants, would provide an understanding of what the subject emphasized here corresponds to in daily life. Şule explained the situation as follows;

No, I didn't take daily life lessons at school. These lessons were in special education, but I didn't take them there either. I don't know how to cook or anything. My family helped me with the smallest thing, I was not responsible for anything, it became a habit for me. I don't do anything unless I have to... My little sister is blind also, goes to primary school and doesn't take those courses either. I would like to study independent movement the most. My family would also get used to it and that I would be a separate individual from them. Now, whenever I have to cross the street when I am leaving the house, my father calls me to ask where am I and how long was it left. If he is at home, he definitely comes with me. But, he has to overcome that!. He asks my brother, who is sighted at the age of 13, to go with me. That is, he tries to make me dependent on my brother who is ten years younger than me. I think if I started using white cane at a young age, I might not have been like this... I am not as practical as someone of my age now, my mother could give me these tasks, I could help her in housework. When I went to school as a boarder, I learned the details of, say, how to fold the shirt from the older sisters at the school, and something started to occur. But, it's not just about laundry, there are a lot of things to do. If I had been taught properly at that time and started doing it, I would be more practical in general, and motivated to do housework.

"Overprotection" is one of the expressions that participants frequently use in relation to families. Mehmet likens families' approach to their disabled children as a disease that its negative effects increase over time. Mehmet;

In fact, something that is a small disease grows and grows and can become a complete problem in the future. Something that was not a problem as a child can become a problem in the future. So, like this thing, it's like the mild onset of a disease, if you spot it early, overprotection is like the onset of a minor illness. In the future, when the age gets older, the family side cannot get used to it, and protectionism continues. However, a person is old enough to do something on his own, protect himself, manage himself, and eat his own food. But, if the family cares too much about him, if feeds him or something else, of course, this is not a good thing, of course it can be a problem.

Daily life education is expected to reduce the anxiety felt by families for their children, so on the contrary, shouldn't they stand on these trainings? Semiha who educated primary school as a boarding student's comments about the issue gives answer to that question;

They are afraid that something bad will happen to us, because they believe that we cannot do anything, they do not know hidden talents of us. My mom must have known about me, but she doesn't... Families limit (their disabled children), they have no other work to do than limiting, they always say don't do that, don't do this!... If I wasn't a self-confident person, I would be sitting at home right now. I tried a little, I did something, so I got this far... They say, how would you go to Kızılay, it's too crowded! I go, so what!... I did not talk with my family to convince, I just went out directly. It depends on action, to me its all about the action, not what is said.

The key point here is the parents' approach that their disabled children cannot do in all situations. Semiha took direct action without needing to persuade her family. But, to some of the participants, it was very difficult to convince families that they could do. Alp told how he struggled with his father to let him go out alone as;

I had epic fights with my father, he didn't let me go out alone, he was afraid for me to be hit by a car or anything, not because I was little, because I cannot see. It was about two to three years ago. But now, my dad calls and asks only, "Where are you, son?". We are over all them now. ... But I struggled almost a year, and then he understood that I can manage myself.

Meltem conveyed her experience with her family in this regard as follows;

If the family says, don't, you cannot do it, get off, then that child cannot do it even she takes lessons at school, if she doesn't get support at home. My father is like that. My mother and my brothers and sisters are not like that. They always say that I am no different, they say I can do anything too. They say to my father that "she have to learn, so let her do it either". Since most of the people in the house say so what my father say does not outweigh. My mother also taught me how to cook, my siblings do not know how to cook...

Alp had to convince his father. Thanks to other family members, there was no need for Meltem to persuade her father. On the other hand, Murat's experience was an example of the situation between siblings, one of whom was totally blind and the other has low vision. 19 years old high school student Murat was blind in one eye and used a special glasses with very thick glass. His twin brother Ali was totally blind. The twins educated at the same high school till last year when Murat failed the class while Ali has begun the university education. Murat took care of his twin brother until last year. He

always helped Ali while eating, during breaks, performing ablution, going to the toilet at the school. It was very difficult for Murat to split up from his twin. He said;

The first time that my brother go out alone was when he began to go to the university. At first, I could not let him to go alone, I could not trust, fear of if anything bad happens to him. But, our school hours did not match when he began to go to the university. Then he has begun to manage himself on his own... I have got used to that situation now. I have always thought that I could not get used to, but I am, thank God, there is nothing to worry about now.

It is often stated that families' awareness of the education of people with disabilities should be increased. However, I came to conclusion from the conveyed thoughts and experiences by the participants that, actually, the awareness needed to be exist is the thought that people with disabilities can live their lives on their own. Because, the perception of yapamaz(cannot do anyway) so dominant that the importance of everyday life and independent movement skills training cannot come to the fore.

The approach of the families to the situation described here actually reveal the perception of the disabled in society in general. To this understanding, a person with disability is an individual who is not able to do on her/his own, therefore cannot do anything in any case. Following this, disabled people must always be together with some other person to eliminate any danger. Thus, only thing that can be done is helping them. Therefore, it is assumed that it is not meaningful to take independent movement or daily life skills courses, while basic education courses such as mathematics or history can be taken.

The families of most of the participants have moved to Ankara for their children's schools for visually disabled. The families support them to have university education and work in a job. In addition, most of the participants have largely got return on their efforts of convincing their families that they are able to do things they want. Although some still struggling, in a sense, ultimately their families are open to responding to the requirements of the participants. However, what the participants told about their friends, reveal basically the different manifestations of the perception of "disabled people cannot do anyway" in different families. One of them is that, some families do not admit the impairment of their family member. Neşe told about this subject as;

Maybe I wouldn't have been able to develop this much without my family. It is very important to accept the disability, some of the disabled families do not accept their children, there are those who hide their visually impaired children. I heard those too, and was shocked. My mother told me that she met a mother of a visually disabled man. She had been hiding his son's partial blindness from their neighbors, and even her sister-in-law for 15 years. For example, we have a neighbor downstairs, the child's eyes are troubled. My mother told them to go to a doctor for the child's eyes, but her mother refuses. Family is very important. Most of the disabled are within four walls, few who dare to go outside.

Not accepting the disorder seems to bring with the concealment of disability. In fact, it appears that it is quite common to hide the disability and the disabled person from society, albeit in different

contexts. Mehmet's expressions about some of his blind friends indicate that, there are also excessively cautious families in this context. Mehmet;

I have many friends, they don't have even a mobile phone, their families did not get a smart phone to them. They could not improve themselves, did not learn to read or anything, and they are so bored at home that they cannot go out, they have nothing to busy with. They do nothing but daydream. They are people who spend two-thirds of their days sleeping. I feel so sorry for them that if they buy a smart phone at an affordable price, they will learn, meet and have friends. Families keep their children away in case they get damaged by the phone. But, this situation is more harmful. I mean, not to send them to school for the fear of what if they break their arms or legs, is not better to captivate them between four walls. There are also those who cannot go to high school after primary school. There are people who spend the rest of their lives at home, there are also people who have never attended school in their lives. There are visually disabled persons whose mothers take them only to special education or something. But, there is no school environment, there is no inclusion environment at there.

Even though not much, the disabled people who were unwanted by their families were also mentioned by participants. For instance, Yeşim said; "My friend's parents used to lock her in the room just because she was blind, and they told her "don't go out for the guests, because you are spilling something, you are getting disgraced." Her grandmother raised my friend." Meltem mentioned about the issue from a different angle that some of families desire to get rid of "burden" of their disabled children;

My ex-boyfriend did not receive any educational support from his family either. They thought that he could not do, he could not read anyway, what he would do in the future even if he went to school. They just pressure him to get a job and get married to live with his own family. Then, he saw that he could do it with the support of me and friends, now he is studying at an university. But, he is still distressed, it is not possible only with the support of friends, when his family brings up this issue again, he stops studying... In general, families do not support education of their disabled child, nor do they believe their children can do anything. For example, there was a Selçuk in primary school, they would not even leave him at home, if his family went to a visit he would go with them, he had no friends, we never saw him after primary school.

Another manifestation of the perception is overprotection, which was mentioned before, and oppression by families on their disabled children. Alp describes those as "oppressive protectionist"(baskıcı-korumacı) families;

Let's call it "oppressive-protectionist" because of their fears about environment, scaring of die or something bad happen. In addition, the thing is, it's not known what the disability is. You lift the cane, but the car does not stop, on the contrary, it honks. Plus, it's bad for us, but good for them(families), I saw this a lot, for example, the man doesn't even know how to open the chocolate package. His family opens it for him, everything has been done for him ready by his family, from his personal care to his shave. Their families are doing harm, they are dulling them. There are such people. It just happened, recently, the man asks me to open the ice cream package, think about it, he was older than me.

The participants' telling about their visually impaired coworkers were concrete examples of what would happen as a result of the lack of daily life skills. Meltem mentioned about a coworker;

Families do not want their children to take life skills lessons in special education, they want them to take basic lessons, but even if they take mathematics, those children cannot do

anything on their own. In our workplace, there is a friend who is very smart and has academic success, but he has not gained any skills and cannot even eat properly. Therefore, he may gets reactions from sighted people. He doesn't clean the table after he ate or anything, we clean it for him.

Participants often mentioned that their visually impaired friends got used to “their comfort”, and also that their families caused it. Erkan's friends give an idea of the extent of this situation and how some people with disabilities in this situation spend their lives after getting married and leaving family home. Erkan;

I did not see people without support from their families, I saw people with disabilities who received too much support. I have a visually impaired friend, for instance, he is 20 years old, but, I mean... if his family is bathing him, there is a problem with it, or if they make his food and bring it in front of him, there is a problem, it is not related to vision. We could not educate families at all, we cannot direct the family that disabled person can also do something within the frame of their abilities. There's a couple, for instance, my friends, they're married, they're both visually impaired. The man is a civil servant, his wife is a housewife, 23-24 years old, so they're almost my age. My friend's mother goes to their home a few days a week, and she cooks enough food, cleaning and ironing. Once, a teacher who gave a course on gaining indoor skills asked my friend to send his wife to the course so that she could learn how to do housework, so that his mother would not get tired. My friend refused him. When the teacher asked him what he will do when his mother passed away, he said, “Then we'll think about it when it comes, I don't want my wife to attend the course”. Later, the teacher spoke to his wife, but she said she was not married to do housework.

The awareness of the trainings of daily life skills in families of people with disabilities cannot even come to the subject in the minds of them, because of the acceptance that “disabled people cannot do”. The common point of that approach and what the participants told about their friends are the manifestations of the same understanding. Although they are very attached to their children, there seems to be a prevailing opinion that the only thing that can be done is to help them. Families not accepting, or hiding disability, hiding their disabled children, preventing them from taking part in social life, or protectionism and overprotection are all actually the results of a similar approach in different family structures from different environments.

4.2 Social Encounters: People on the Street

In everyday life, the reaction of people to a disabled person on the street is one of the important indicators of the society's approach to disability. Based on the findings during the fieldwork, the society's behavior towards people with visual disabilities in the street is more than neutral. What Mehmet told summarizes the situation as follows;

I had misunderstood a little (in times before he regularly go out alone), I used to think no one would get help in the past, I would say how to go somewhere. Those who are sightless help the other sightless to become conscious. Sometimes the sighted doesn't know that. When I found out that I could get help from other people(sighted people), I was very happy.

As participants often mentioned, when especially accessibility issues are taken into consideration, knowing that there always will be someone to help to find directions, crossing the road in traffic, to get on the right subway or bus, and so on is an important factor that increases visually impaired people's motivation for going outside alone.

Considering the reasons why people with disabilities are helped so widely, it is seen that, to help a visually disabled person is a social behavior coded culturally according to the data I have gained from the participants' experiences. These cultural codes have different sources. One of them can be described as religious aspects of interpersonal relations. It is possible to decode these cultural codes based on some statements of the participants. One of these cultural codes is that, visually impaired persons, especially male ones, are called *hâfiz* by some of the people. *Hâfiz* is a person who knows the Qur'an completely by heart (TDK, 2019, my translation). Historically, it is stated that some visually impaired people used to be an *hâfiz* in mosques during the Ottoman period, and therefore, visually impaired people were addressed as *hâfiz* among the public (Subaşıoğlu et al., 2019).

Erkan who was partially sighted conveyed his experiences regarding that as follows;

One day we were walking on the sidewalk with a friend, he had a white cane in his hand, someone entered our arms, we didn't need that, but, we didn't refuse that it was a gentle behavior. Some uncles (old men) said a lot of things, like you're the trust of God to us, something like that. I mean, really the way society looks at us is so interesting, this is a common thing, I don't know how to tell it. For example, there is a general belief that, they think all the visually impaired are hâfiz. Once, I was looking for a cell phone with voice program, when I was trying to explain it to the seller, he interrupted me and said, "I know I know, my uncle's son is an hâfiz like you, he uses that model too". For them we are all hâfiz.

Accepting a visually disabled person as an *hâfiz* inevitably means that, people are supposing them as persons who are religiously respected and therefore inevitably "innocent". However, Mustafa did not agree with them;

Sometimes they say halal (well done) you go out and you walk around alone. Some people say "your eye of the heart is open". (According to people) we do not have any sin, usually old people think so, they call us hâfiz. It doesn't bother me, but the discourse isn't right... Because, okay, we don't see, we are sightless, but we can sin so like other people, we're no different. Okay, we started to the life 0-1 behind, but that doesn't mean we don't sin.

Semiha, on the other hand, talked about a problematic understanding of how people categorize the disabled in terms of religion;

Some says your prayer would be accepted. According to them, Allah has taken our eyes, then Allah will accept our prayer. Okay, Allah says in the Qur'an that, "we reward with heaven those whom we have taken their eyes", but there are conditions, and only Allah knows them... People always ask me to pray for them, then I say, why, you pray for me. Sometimes they say "God will help you" as if they don't need help, and I say, "May God help you". What they meant is that, they are sighted, so they are a complete human. But they are not, nobody is.

It is understood that because of the religious beliefs, some people in a sense respect the visually impaired just because they are sightless, or some others think that visually disabled are deficient for

the same reason. Basically, the fact that people keep the visually impaired separate from themselves. In addition, what Melek and Neşe told gives an idea about other aspects of the subject;

Melek;

A friend of mine told me that, recently when she was walking down the road, a man came up to her and asked where she was going, then walked with her. But, while walking, the man was constantly counting. My friend asked what he was counting but could not get any answer. Then, when he came to number 40, he left in the middle of the road when saying "anyone who takes a visually impaired for 40 steps deserves heaven", and leaves. More things like this are happening every day.

Neşe;

Well, people always say that "don't be sad, it must be something blessed, it is the will of god", like that. Am I already a person who is upset?! Isn't it clear that I am not sorry, isn't that appears so?! But, I don't want to break their heart, so I say, thank you, I say yes, here is the world of exam, just like they say. There are too many people who say that because ... They say, "you don't see, how beautiful it is, you don't see bad things". This is said a lot. It is as if we do not aware of the events, I mean, but we hear them!.

Those reactions in society due to religious reasons are very interesting, but a larger study is needed to make a generalization. However, in those examples, too, people keep the disabled separate from themselves. In all these experiences, it is seen that the bias, which causes to consider disabled people as someone that they are actually not, have determined the social approach to visually disabled participants.

On the other hand, whether its cultural source is religion or not, it looks like that, to help a sightless person on the street is an accepted social behavior. According to the participants, this approach prevails in society. They often interpreted the reason for this as a result of people's concerns about the disabled. Mehmet said; "On the streets people are persistently helping because they fear that something bad will happen to a disabled person. As they think that the disabled cannot go anywhere on their own, they worry about a disabled person." And, Şule said that;

There are collectivist cultures, there are individualistic cultures. I think we have a situation that cannot go from collectivist to individualistic. Therefore, nobody could say, "who cares! she gets help if she needs". People feel responsible themselves for someone else.

In addition to the concern, it is understood that there is a lack of information about disabled people even in their relatively close environment. Melek's experience in this matter was as follows;

I also had a lot of problems with my grandmother and grandfather. My grandfather called last day, he said, "where is your mother and father; how they leave you alone!", he started getting angry, then I said see you and I hang up. How old am I, just think about it, but no! They are in the town, we are here, they do not know much about my life here. Society in general is a well-intention, but with lack of knowledge... People's goal is to help, they say, "I will help then no matter how to", there is no empathy.

As can be seen in these examples, besides being afraid and feeling a kind of responsibility for the disabled, not having information about the way of life of a sightless person is also a factor of the

approach towards disabled people. Participants emphasized the negative results of this kind of acting that not always serve for the purpose of helping, as Melek said;

People are trying to help in the way of they feel correct. The main purpose is to help, they do it to relieve their conscience, in the mood of "I am a good person". I recently went out of the school, I will walk off the road and walk straight across. A woman fall straight into my arm, this is a serious annoyance by the way, they go directly into my arm without asking. Anyways, we talked a lot, but she left me before crossing the street. We just walked on that road but what I needed was to get me across... Another example, The Ege district bus stop is an extremely crowded one, I got on the bus from there, an old uncle, as always old guys doing this by the way, in the queue who did not get on the bus from behind, hit the bus's window, everyone inside said "what happened", he said "there is a blind inside, let her sit". So, maybe it's a very good behavior, but sit yourself first and then ask me!. The way it is made is very annoying.

In addition to those momentary concrete difficulties, participants frequently stated that they were very uncomfortable with not being perceived as an individual. Yeşim told about the issue as follows;

A couple of days ago, my friend was with me but did not interfere on purpose to me, so that I could learn to go on my own. But, some around came immediately to help. My friend told them "' am with her, if necessary I can help", they said, "'f you are her friend why don't you help her!'. They argued for a while... For instance, my brother had a wedding this summer. My sister and I went to the hairdresser. The woman who did my makeup made a sign to my sister, a hand gesture, I could feel it. My sister said that "she can only see the light, she can see the other person as dark, she cannot choose faces". Then I said to the woman, "don't get me wrong, but it's me, and you're talking about me right now. You can ask me that question instead of my sister". The woman said she didn't mean to offend me. Then I said, "aren't you more offended by acting like this?" And then she said "you got me wrong", so-so. I'm so angry, she could ask me!

In reference to the participants' told, helping a disabled person is a necessity of being a good member of society in people's understanding. It is accepted that this is what needs to be done. But, on the other hand, participants emphasized the negative results of not having information about the way of life of a disabled person and not being perceived as an individual. In addition, a kind of problematic categorization that participants experience during their usual daily interactions creates a distinction between people with disabilities and those others. The perception that visually impaired people cannot do anything on their own, hence cannot go anywhere by themselves, is so ingrained in the public sense that people do not even think to ask the disabled before they act.

If the act of taking the arm of blind people without asking is experienced in daily life this much, then it is a clue about the society. This kind of acting, in the name of helping, is an indicator of society's perspective on disabled people. And, if it was mentioned this much as an annoying behavior felt always by the visually disabled people, then it is not just a helping behavior, it is a problematic approach of the society about disabled people. That is, it is a concrete sign of approach of the community that will have reflections in every institution of society such as education or the state.

4.3 Education: Optional Self-sufficiency Training

One day students organized a surprise birthday party to one of their friends at ODED. Everybody brought something to eat and drink. There were eight visually impaired students who were or older than 18 years old, three teachers including me, two mothers of students and a manager of the association. Four of the students were totally blind, others were low vision in different ratios. We all sat to the table full of foods and beverages. During the party I observed that, blind students did not attempt to get their own food and drink by themselves, low vision students spontaneously help their totally blind friends to get food and beverages. The places of foods and drinks on the table were not identified, but told what they were to the blind students, then were asked what they wanted to eat or drink. Low visually disabled students put whatever their blind friends wanted on a plate and gave them to their hands, as mothers also did.

It can be thought that this birthday party was an extraordinary situation that blind students could not get their own food or beverages without any help. But in fact it was not. During the time I spent at ODED there were four total blind students there, others were partially sighted. 22 years old Mehmet was the only totally blind one who got his hot beverages by himself from the kitchen. Other blind students were always asking for help from their low vision friends to get especially hot drinks like tea or coffee. Mehmet told me that, he learned to cook and get tea or coffee without burning his hands at a special education center, not at the school for the blind. Mehmet said; "I thought that it was so hard to cook tea or coffee before. I couldn't touch anything hot before, when I got this training I was 15-16 years old." Mehmet was also using a white cane. He independently could come to and also went from ODED by himself unlike other blind students. Others were taken to and went from ODED with their mother, father, sister and cousins. They do not use white cane. Mehmet said that he started going out on his own permanently last year, for attending to a computer course;

Other institutions, associations and the primary school, were also helped me to move independently. The school introduced me to the cane. At the age of 9, I got cane training for 2-3 weeks, that was all. I have never needed to have a cane training for the school because the inside of the school was a place I knew. I never even went alone when I needed to go out of school... My blind teachers always said that you would eventually meet the white cane, you'd better meet now, which was weird for me when I was 8-9. I used to think that that day would never come, I would never go out by myself, I would always go out with my mother, I always would go with my mother so I wouldn't have trouble. But that day came, I'm outside by myself now. I'm glad I went to special education (center), cane training is given to those who want, even the training is given outside the center itself. Those are, get on the bus, get off the bus, dialogue training, how to overcome the fears... After training there, I went out on the street. Otherwise it would be difficult.

The lack of daily life and independent movement skills of the people at ODED and Mehmet's experience in acquiring these skills, brings to mind the question of how, where and under what conditions such important skills training can be obtained.

The official regulations of the state regarding the education of persons with disabilities are carried out under the title of *Özel Eğitim*(Special Education) with the regulations and directives published on the basis of relevant laws and decree laws(MEB, 2018:Article 3). Accordingly, the goal is to ensure that individuals who require special education can exercise their right to receive general and vocational education in line with the general objectives and basic principles of Turkish National Education(Decree Law No. 573, 1997, article 1). Here, the individual requiring special education is defined as the individual who differs significantly from the level expected from her/his peers in terms of individual characteristics and educational competencies(Decree Law no:573, 1997, article 3/a)¹⁰, and special education is defined as, carried out education in appropriate environments with specially trained personnel and with developed programs to meet the educational and social needs of these individuals(Decree Law No. 573, 1997, article 3/b).

According to the *Özel Eğitim Hizmetleri Yönetmeliği* (Special Education Services Regulation, Official Gazette no 30471 of 07.07.2018), in other saying, according to the determined policies, starting special education at an early age and developing individualized education models are among the basic principles, as well as the beginning of the education of those who need special education with pre-school education, together with primary education, are included in the scope of compulsory education. In addition to these, policies based on ensuring active participation of families in every stage of the special education process, and prioritizing their education with other individuals by making the necessary adaptations were determined(MEB, 2018).

In the light of these policies, it is taken as basis that the education of disabled individuals be carried out principally by schools where inclusive education is applied. In addition, it has been decided that it will be run by special education schools, (such as primary education schools for the visually impaired), and special education and rehabilitation centers ("special education" as the participants call it short) within the scope of special education institutions(MEB, 2018). According to the relevant regulation, it is necessary to apply to *Rehberlik ve Araştırma Merkezi* (Guidance and Research Center [RAM]) in the region where the disabled person is located in order to provide special education(Decree Law on Special Education No.573, 1997). The application can be made by the family / guardian or school officials of the disabled person or by himself / herself if s/he is over 18. Educational evaluation, identification and orientation are made to the disabled person by the RAM. In line with the report prepared as a result of this guidance, it was said that the implementation part of the special education is prepared by the "individualized education program development unit" consisting of the individual's teachers, parents / guardian, the guidance teacher / psychologist of the institution, the directors of the institution and the disabled person herself/himself(MEB, 2012, article 5-15-16).

¹⁰ In the law, the individual in need of special education are, disabled individuals and gifted individuals. As of the subject of this study, the legislation explanations were made only for disabled individual here.

The support education expenses of the disabled individuals stated here are paid by the Ministry of National Education(MEB, 2012, article 31)¹¹

The training on daily life, self-care and independent movement skills and raising awareness of the family, which are emphasized in this part, are mostly left to special education and rehabilitation centers and / or special education and rehabilitation units in special education school, if any(MEB,2012). Another important issue is that, if it is wanted to be taken, special training including supportive training should be requested by the disabled or their families as explained above. But still, when looking at the perspective of general order, the experts of the subject states that, as mentioned before, the official regulations within the scope of special education services is quite extensive and similar to many leading countries in this regard(Çakıroğlu&Melekoğlu, 2014; Meral&Turnbull,2014; Ochoa et al., 2017). However, the information I have gained from the participants reveals that there are serious problems in the implementation of these written regulations.

All of the participants I interviewed have had high school education in schools providing inclusive education, all but two studied primary school in a school for visually impaired. It is understood that the skills training courses were one of the elective ones which were given about two hours a week at schools. In addition, some of the interviewees told me that there were not any courses like that during their education years where they were educated primary school for visually impaired. All of the participants stated that they continued to Special Education Centers throughout their education lives (and still are). However, in these centers, they preferred the same courses such as mathematics taken in formal education to prepare for the university entrance exam and Engelli Kamu Personel Seçme Sınavı (Disabled Public Personnel Selection Examination - [EKPSS¹²]) rather than daily life and independent movement skills trainings.

Alp was the only one person among fifteen participants of in-depth interviews who told me that he learned all the activities he needed at training courses for those kind of daily life needs at visually disabled school he were educated. Alp is a 18 years old inborn moon-blind (night blind) high school student. The interview was performed in day light so he said he can see my face, but he cannot read anything even in mornings, however he could read when he was a child. His ability to see is decreasing every passing year and he knows that he will be completely blind as he gets older. Alp, explained trainings he took for daily living as follows;

¹¹ Monetary support for disabled individuals in special education schools and special education and rehabilitation centers for 2020 was determined as TL 790 per month for individual education and TL 221 per month for group education, excluding value added tax(Hazine ve Maliye Bakanlığı 2020) In the same year, the minimum wage was set at TL 2.324,70, excluding taxes.

¹² EKPSS:"The central examination made according to the disability groups and educational status of the disabled people who graduated from secondary education, associate degree and undergraduate which the results are used for recruitment of State official and worker stuff of public institutions and organizations"(Devlet Personel Başkanlığı 2014: Article 4 / d , my translation). EKPSS is "Prepared by ÖSYM (the Measuring, Selection and Placement Center) in according with 'Regulation on the Selection Examination for Public Personnel with Disabilities and the Admission of Disabled Persons to Civil Servants' accordingly the provisions of the Protocol between the Ministry of Family and Social Policies, the Ministry of Health, the State Personnel Presidency and the Measuring, Selection and Placement Center, EKPSS is an examination system consisting steps of application, examination and evaluate examination results"(ÖSYM 2021, my translation).

Mattress covering, ironing, chasing the wall, walking with a cane, pendulum cane, crossed cane, learned them all at school. We had a free activity lesson at school, 2 hours a week. There were 5-pupil in the class. How to put a wardrobe, how to fold clothes, etc. It was up to the class teacher to determine whether these training would take place in that lesson. My teacher would... Those training were very effective, they taught us how to behave when we entered an environment. They gave us clockwise training. For example, suppose I describe the table to someone who does not see, I describe it on a dining table that there is a salad in 12 clockwise, or cutlery is in 10 clockwise...

Since Alp would be completely blind in the future, they decided that he should receive appropriate training with his family. His teacher blindfolded him and trained him to acquire the skills he would need in the future. Alp said that he was lucky to have such a class teacher. Because, the teacher had given him and his classmates more than two hours of training a week and had them do exercises in each part of the school where they could move on their own.

As a completely reverse experience, 21 years old totally blind Mustafa stated that he did not have those trainings during his education period at primary school for visually disabled. Mustafa emphasized that he had troubles since he did not receive these trainings as a child. Mustafa said;

At my time, there was no any course named as independent movement or daily life, nothing, still there is not any, I guess... I went to independent movement courses long after, at a special education center. I got the techniques only, then I had progressed it by myself. I had somehow taken care of "daily life" by myself. Now, it is hard for me to get tea, putting tea on a cup etc... but somehow I manage it. I cannot cook, cannot ironing, I can fold clothes. I don't shop alone, I'm more comfortable with someone else, usually with my mom. There should be practical life (independent daily life skills and independent movement skills) courses at the primary school, it has been given at special education centers but, there is a proverb, "as the twig is bent, so grows the tree". If we had these courses at our time maybe we wouldn't effort to overcome them now. Always being dependent on the family is, I mean, bad. God forbid, when something happens to the family of the disabled person in the future, then what he gains will gain a lot, he will be able to stand alone.

After the age of 17, Mustafa learned to use a cane in the special education center as well as with the support of his friends, and started going out on his own. Apart from that, he mentioned he received help from his mother for his needs that require daily life skills. Participants who were boarding students at the school for the visually impaired stated that they received some daily life skills training, especially personal self-care skills, from older visually impaired students and dormitory supervisors. Meltem;

There were no practical life lessons. We learned because we were boarding students. There were older sisters, they taught how to make up a bed, how to arrange a wardrobe and so on. I was going to my family house on the weekend and they were teaching also. We learned how to cook tea, cooking, etc. by living. The sister who took care of the dormitory was entering the bathroom and intervening, if anybody could not have bath by herself... My teacher taught the cane in primary school, he was our history teacher; I asked him. Friday had reserved the last lesson hour for this, he was visually disabled also.

Semiha who also was used to be a boarding student, emphasized that since she is a brave person, she learned to meet the needs of independent movement by trying over and over again;

We had an elective course. We made cakes and tea in those classes... I took that course for a semester and I couldn't get it again, because there was no place for everyone. I have trained my own self. These courses should be taught to everyone and should not be elective, because it is unclear what will happen in the future. Oh, I do it because I'm brave, it does not matter if it is for the first time, I can. Everything has a practical way to do, potato peeler, tomato peeler. Nobody taught me how to peel potatoes, I learned it by myself... Not only having special trainings, but also families are needed to be raised awareness. Families do not let their children to do those kind of things, they scare, they say "stop stop knife", but you cannot cut without a knife. These courses must be given at school.

Most of the participants remarked similar points with Semiha and Mustafa that there should be daily life skills and independent movement skills courses at primary schools, and families should also be made aware of this issue. But, four of them have different ideas. To Rıdvan, these courses were not necessary, but would be good if there were, in this manner he could do things he can now a couple of years early. Rıdvan was coming to ODED with his cousin and returning home with his father. He could not get any hot drinks from the kitchen by himself. Meltem thinks that taking practical life courses would have been set basic lessons back at schools. Because, those courses should be given one by one for a productive training, as in special education centers. But at schools, it is not like that, so, it's wasted time reserved at school, therefore special education centers were good for those kind of daily life training courses. Melek said that those courses were needed to be given both to children and their families, not only to children. Families should be thought those trainings and they must be provided to train their own children.

Here, it should be reminded that all participants are visually impaired since childhood, (most of them congenitally), and they are now young adults. They have experienced the disability so they know what they need thus what should be done. The common opinion of all is that, daily life skills and independent movement skills training should be taken in childhood. So, some of them especially expressed regret that they did not take these lessons when they had the opportunity to take them at an early age, just like Mehmet;

I don't know, but it would be better if I had daily living skills lessons, I wish it was compulsory for me... I think the priority should be these lessons... The priority of schools is always exams, lessons, as it is though that children learn others somehow. But truth of the matter is different, so you have to be trained at a young age.

In addition to its negative effects on quality of life, there may be an explanation for the fact that the participants were not perceived as self-sufficient adults in the society they were very disturbed. In other words, they were perceived as needy by people because they did not develop daily life skills and independent movement skills that could actually be acquired if appropriate training was taken. Consequently, apart from providing independent movement training with the personal effort of some teachers, the skills training was ignored in the educational lives of the participants. I am of the opinion that the reason for this indifference between regulations and practices on such an essential subject cannot be addressed only within the framework of "general education problems". Since the importance of daily life skills and independent movement skills for an individual would not be

unknown by school administrators or educators, there should be a matter of understanding here. It is not wrong to conclude, in the light of participants' experiences, the mind of "disabled people cannot live on their own anyway" must have prevailed.

In fact, apart from the skills training issue, it is necessary to take into account what the participants mentioned about the basic education lessons in order to understand the approach. A few of the participants noted that, some of their teachers did additional lessons specifically for them. Some of them stated that, teachers frequently helped them to pass the exams and most of them said that, they were favored by their teachers and school administrators during their inclusion education period. So much so that, some of them described this situation as discrimination in a negative sense, like Rıdvan;

I used (positive) discrimination even though I don't like it very much. That's why I passed the lessons very comfortably. Once, I asked the teacher if I was going to take an exam in English. The teacher asked me to translate a very simple sentence in English to Turkish, and then said "okay you passed the class". It was not an appropriate oral exam either. Some others objected but as the teacher said so... I was happy about the situation, even though I didn't want it. Now, I'm not saying I wish the teacher had given me an exam. I do not like distinction, because I am what you are. Although I don't like it, I still benefit from it. I had another teacher; he never separated me from anyone else. I had the same exams as everyone else. It should be whatever the rule of the school is. In some cases, I should not be put on the same place with the sighted person of course. But, it bothers me that people keep us separate in all kinds of situations.

Participants underlined that they were favored in the name of helping. They also stated that, their teachers generally did not think that a visually impaired person would be successful in the relevant course, or they did not know how to teach a visually impaired person, or they did not want to deal with it. Therefore, it is not wrong to say that, the understanding of *yapamaz*(cannot do) is evident in the perspectives of educators throughout their school life. And, help-only approach, again, manifest itself in a different context.

As it is understood according to all accounts of the participants, techniques to accomplish daily life and independent movement necessities was pushed aside and not commonly learned on time, that is when growing up. It became clear from the statements of the participants that, this situation had negative effects on the daily life quality of the visually impaired. In addition, this may be one of the reasons why people consider disabled people as incompetent. The formal education regulation, in this context, was arranged on the basis of the fact that the disabled receive special education if they request, and within this scope, daily life skills and independent movement skills courses are optional. School administrators, education authorities, teachers, families and even some people with disabilities have a perception that the disabled cannot do anyway. The fact that skills training is being put aside in practice shows that, the help-only approach prevails in the education life.

4.4 Workplace : Income-only Practices

It was frequently mentioned in interviews and in our private conversations that families insisted on getting a job to their children. The situation can be understood more concretely in Meltem's experiences who was partially sighted and has spine problem. She was a university student and also has been working for three years, in the staff as a public servant. Meltem's mother and older brother were very supportive of her education. But on the contrary, her father and grandparents opposed her going to school. As she said, they still believed it was unnecessary for Meltem to have a university education while they were supporting her non-disabled siblings' education. Meltem explained the reason for this as follows;

Everyone has the feeling that the visually impaired not able to do anything. My father and grandparents used to say that too, they always said to me that "you are not able to do it, you cannot go any further", when I was at primary school. Then I went to high school, it was the same again, my father said, "get a job, what are you doing here in the school, you cannot progress anyway". My mother and brother intervened, thanks to them, so that I could continue my education. Then nobody intervened anymore, I also was grew up, I was able to understand, I also had a right to speak for myself, so I am continue to study at my university.

It may be confusing to be against to school while insisting of getting a job, when the dominant thought was "cannot do". Meltem explained it as;

The mentality is that, going to school is just a waste of time, because even if she is educated, she will not be able to progress in the field she is educated. Therefore, it may be a desk job, or anything else which she is able to do, because there are a lot of disable people who are working at public institutions as public servants. Get to work, earn your money, save your life... The logic of "this is what you are able to do the most".

There are two sides to the issue of working life here. The first is that, families and disabled people are familiar with disabled persons who are employed at state institutions. The perception of incapacity that is internalized on independent movement or education issues seems to have broken down about working in the state.

The other side is the underlying and ongoing manifestations of the perception of "disabled people cannot do anyway" in the working life of the visually impaired before their colleagues and supervisors, even in the approach of the disabled themselves and their families. Meltem pointed out that this understanding will not be improved over time. Because;

People make the disabled completely lazy. The people with disabilities are put in a workplace but they do nothing there, or not continue their education. Because, they think that they already have a salary then they don't need to do something or study anymore.

The perspective on the employment of the disabled is shaped within the framework of the right to work in general. However, the experiences show that the application is insufficient and barren as it fosters the perception of "needy disabled". In other words, with positive discrimination implementation, disabled people get a job but do not work. Because, according to the participants, an

income was provided to disabled people, but providing a social worth and self-well being were mostly overlooked. It is needed to highlight here that, what families insisted here is not just to get any job, but having a job as a public servant in the state and earn a monthly guaranteed income. During the study, working at the private sector was very rarely mentioned, which was only about the family businesses or affirmative businesses. In fact, the statements of the interviewees about whether they would consider to work or not were mostly starting with the words “I have taken”, or “I want to take”, or “I will take EKPSS”.

There are two main sources of the fact that disabled people's work in the state has become such a widespread understanding, as well as the general trust in the state in society. First is, the public institutions and organizations in accordance with the relevant laws in Turkey are obliged to employ disabled staff at 3% since 1965(Act on Civil Servants No.657, 1965; article 53). The other reason is that, there is a different and, according to participants, an easier the state recruitment procedure for people with disabilities. The recruitment of public personnel is carried out through a central exam, However, recruitment of disabled citizens is made separately with a central examination, EKPSS, opened only for disabled people until 2012¹³.

The youth unemployment rate of the 15-24 age group in Turkey, announced in October 2019 by Turkish Statistical Institute [Turkstat] was 25.3%(Turkstat, 2020). From this point of view, a separate recruitment procedure with EKPSS for the disabled and 3% disabled public personnel quota are both the positive discrimination implementations that contribute to the participation of disabled people in business life as well as social life. However, the experience of the participants on this issue, as detailed in follows, shows that the perception of “the disabled cannot do” is immediately felt after they were employed in a position.

Semiha, Şule, Melek and Meltem were working and at the same time, all of them continue their undergraduate education. They were working at schools and/or in the switchboards of institutions. Three of them had a job in the position of the public servant(hizmetli kadrosu), one of them employed as the official staff which EKPSS scores must be high in order to start working in that position.

Other participants of the in-depth interview were not working for different reasons. Aydan said that she will have to work in the futura after the university, so she did not want to work already. Neşe said that she wanted to work but her family would not let her by saying she was too young to work. Alp, Murat, Yeşim and Esra were not working because they continued their high school education. Rıdvan and Mehmet said that they had no time to work as they were preparing for the university entrance exam, but they could consider to find a job in the future. Erkan stated that he did not want to work with the concern that he would be asked to leave the undergraduation by the workplace. Elif was

¹³ The first exam held in accordance with the regulation that entered into force with the Official Gazette dated 3 October 2011 and numbered 28073 was *Özürlü Memur Seçme Sınavı*.

preparing for EKPSS at a special education center. And, Mustafa was the only person among the interviewees who said that he wanted but could not work, because he failed in EKPSS.

Yet, some of the participants did some small works especially in the summer to earn money. Murat was helping his father in his restaurant and his uncle in the grocery store. Alp sold water in parks when he was a kid, and had been playing baglama with his band at weddings or circumcision feasts for several years. During summers, Rıdvan worked with his father, uncle and grandfather at district bazaars to sell what his family produced in the village. However, he specifically stated that he did not count as a work what he did there. Rıdvan said;

There were times I haven't been home for a week from the bazaar. I slept there, lived there with my grandfather, uncle and father. We sell melon, bulgur and all kinds of things, and then we come back when the goods were finished. But that's not working life. Because, we do business but not that much... I have sold something, but I am not as active as my father and uncle. People bought at what price I said at bazaar. But, they try to get some discounts from my father. If I say 7 TL, they buy it at that price, but if my father says 5 TL, they want a discount. I think this happens because of this, you know, my eyes. This is not good at all, even for my benefit. Actually, it is not for my benefit, let's earn 25 kurus per kilo, so what. It doesn't work for me, I don't like it, anyway, people should bargain with me too, it bothers me.

Bargaining at the street markets is a kind of Turkish tradition. Therefore, Rıdvan wanted to be accepted as a regular salesman, but people hesitate even bargaining with him, in the name of to help him. If he could pass the university entrance exam he will be the first who have university education in his family and close relatives. And, it looks that after that, he would call what he do as the work.

Elif, who was studying in a university, said that her only goal was to save money and travel, so, she wanted to work for it. For this purpose, she was preparing for EKPSS at a special education center. But, she also had hesitations;

Many people dropped out of their education because their directors at working places did not allow those who were both public servants and wanted to study. A friend of mine whom I talk to constantly, was in the servant staff, recently transferred to the officer staff. She, works at a school, looks at phones, three people in one room. My friend cannot see texts, cannot log into the computer or something, but she's doing her best. Others were gossiping about my friend, like, she could not work, she was sitting idle or something. She is very bored at work. She graduated from university as a teacher, but could not be appointed.

Not being employed in the field of education due to disability is an issue that requires research. However, it should be noted that, this is a topic that participants often talk about. For instance, Erkan thought that he would not be able to find a job after graduating from the department where he was studying at the university. Therefore, he was preparing for the university entrance exam again for another department with the possibility of finding a job later on. He said; "There is noone like me, it is not a field preferred by visually impaired people. I think it would be disadvantageous for me to be visually impaired there, because again, this comes from the social perception of being unable to do it." Erkan's other expression on the matter of the working environments was like a summary of what was frequently talked both in the interviews and in private conversations at ODED;

Actually, my friends do not have a job, most of them are in the service staff. Theoretically, their job is to be a janitor; errands, cleaning, but in practice people do not make them work, they also don't want to do works. The managers or other personnel are not experienced in this matter; they have not encountered visually impaired or any disability groups before. My friends are already used to not working, they don't know what job they can do, so they sit down and don't do business. All of my acquaintances are like that, they only drink tea at work, rarely do such work.

On the other hand, Melek has a job at a telephone exchange in a high school and is also studying at the university. She is very satisfied with her job, because the principal and the assistant principals don't cause problems and she can continue her classes at undergraduation. But, at first she did not want to work, because she was very afraid that the managers would not allow her classes. Therefore, before choosing a workplace she researched them and spoke with a couple of managers . Melek said;

I came across a manager who was nervous, he said "I'm not going to make you work, you come, sit only and get your salary, what job should I give you?." These behaviors are both personal and also there are gaps in the regulation. The report of us given to workplaces states that, we should not be made work in jobs that require vision. People think that all works require vision. Therefore, they do not know what we can do. There's no job description that doesn't require seeing, and most workplaces don't have a telephone exchange. The people who make these regulations are people who are very out of touch, people who have never seen visually impaired people in their lives. They don't know.

Şule has been working in a ministry, switchboard for about three years. Since her EKPSS score was high, she started her public service from the state official staff. But, she was not as satisfied with her job as Melek. She said its reason as; "Because, they sent me directly to the telephone exchange from the very beginning, because I am blind. But it is okay for me in a way, because when it is in the central building, the work is half a day, so it makes it easier to go to my classes." It was understood from both those examples that, it was not clear what the job to be done was, but they have a workplace where they can get a salary. The measure of satisfaction with the workplace was not the work done, but the fact that university education was not prevented.

There is a point to distinguish here, it is self-evident that persons with impairments would owned certain limitations which handicap their employability. But, the extent of handicap does depend largely on the complex interaction of the individual, the impairment, environment, society and culture (Encyclopedia of Disability, 2006:583-589). The working experiences of Meltem and Semiha are exemplary in order to understand the practical equivalents of what is meant here; Semiha took the EKPSS in the last year of high school and started working as a civil servant candidate in her first workplace. She passed the university entrance exam in the same period. However, since her university was in another city, she had to freeze her enrollment for a year and waited from her candidacy position to become a full civil servant. When we met, she just started both her university education and the second job she was appointed to. She was very satisfied with both workplaces, her own performance

and also work motivation. In both positions, the workplace was schools. She told about her working life as follows;

When I got my first job last year, the environment is not for us I thought, I was saying what to do here. But then, be sure, I picked up the trash, mopped the floors, I said that if I am paid, I have to do these. I worked like this for a month. Then I said that the library of this school is not a library, it is like a book depot, it should be activated. "I will put here in an order, if you help", I said. They did. They got the materials, I separated the books, I wrote Braille again, we opened the library on the 23rd of November. The children were so longing for a library, I realized that. We started to give books. Then the phone was given to me, they said you answer the phones now. The guidance teacher saw that I was playing baglama, asked me teach the flute to children. So, I taught flute to the children. I brewed tea in the summer, looked at the phones, I was getting the registration documents. Then I was appointed to the full staff. I went to my new workplace, a primary school, talked to the principal, he said "do whatever you want here". Now I am also interested in the library there. When I got there, my job will be easier, the principal said "give me your education curriculum, the children will come to the library according to it". I will also show my abilities there over time.

As it was mentioned above, Meltem has been working for three years. She also worked in two workplaces but had a lot of trouble at the first one.

The principal first said that if I passed the university exam, I could continue my classes, but after I passed the exam, he did not allow me. He was constantly saying "I can force you to do cleaning works, but I don't for my humanity". He also had the similar thoughts as my father and others, that the disabled cannot do, disabled cannot advance in the career. I had a lot of trouble. There were others in the servant staff there, they were doing desk job but also cleaning, because they were "normal". I was doing business there, looking at the phone, absenteeism reports, errands, was doing more work than where I am now. Since I was a candidate for a year, I could not ask for an appointment. When my candidacy was lifted, I wanted my appointment immediately. Now my job is comfortable and I am continuing my university education. In my opinion, there is the idea that, a disabled person cannot do anything because they are disabled, they cannot be at the same level as a person who is sighted. I was the same as the others there in terms of staff position. About functionally, they were better than me because it was my first job and I was a visually disabled person. But now, I do what they do, also in functionally.

The experiences of the participants in working life show themselves as different reflections of the understanding of the disabled, albeit in different versions. That is, bargaining with a visually impaired seller is undesirable. It almost cannot be imagined that a visually impaired employee can also produce work. In such a way, it was not even necessary to specify what jobs the visually impaired would do in the official articles on the subject. Or, if the participants are lucky, and also struggle enough, they may find things to do with their supervisors and colleagues at work.

The issue here is not only that there is an acceptance in the society as help-only approach to disabled which shapes the behavior to people with disabilities on the street. The main issue which directly affects the life quality of the disabled is that, this situation is internalized by the society. Such that, even there is some positive discrimination regulations like EKPSS given overhead, when it comes to practices in daily life it is not working effectively, as it is deficient. It does not allow an individual to use his / her potential. It only provides "financial help" to a disabled person, not support people with disabilities to contribute to society and themselves. Because the practice here is based on

the assumption that the disabled person does not have the potential and cannot do so, by the person with a disability, his/her family, those in the workplace and even those who make the relevant legal arrangements, that is, by the society in general.

4.5 State: from Disability Rights to Help-based Practices

As stated above, one of the issues mainly emphasized by the participants was the lack of awareness of the families of the disabled. When it comes to raising awareness in any context, state practices need to be discussed. *Engelliler için Bilgilendirme Rehberi-2019* (Information Guide for Disabled-2019) which was prepared by *Engelli ve Yaşlı Hizmetleri Genel Müdürlüğü* (Directorate General of Services for Persons with Disabilities and the Elderly[EYHGM]) has some clues to the question of the government's approach to the issue. It was written there that ;

Family education is an education that includes guidance and counseling services to contribute to the education of the disabled individual at all educational levels. Family education services are prepared and carried out by guidance and research centers, special education schools and institutions, and schools where inclusive practices are carried out. If needed, this service can be carried out at home(EYHGM 2019:18-19,my translation).

The expressions here denotes that the necessity of raising the awareness of the family was recognized by the state. But, there was no further information about the implementation of this topic in the guide. In fact, what was written here is in accordance with what is stated in the above-mentioned legislation on education of people with disabilities in almost every stage of special education. However, although the education of the family is frequently mentioned in the legislation, an arrangement on how this education should be done in practice has not been found. Considering this guide explained below, it was seen that raising awareness was not about living the daily life of the disabled as an independent individual without any help. It was understood that informing the family about the services and rights provided by the state to the disabled was the main purpose within the scope of family education.

The contents of the guide give provides insight on the issues that the state emphasizes on implementation about disability. It was written that “This guide is intended to provide information on the rights and services currently available to people with disabilities”(EYHGM, 2019:4,my translation). The guide informs about how to obtain the health board report for disabled people and followed by how to get the disabled identity card¹⁴. Besides, information has been given about health rights, education rights, right to early retirement, legal rights against discrimination, CRPD¹⁵, ALO183

¹⁴ Disabled identity card contains information of disabled people who lost their physical, mental, sensory and social abilities at a rate of forty percent or more due to congenital or subsequent reasons. It is used to benefit from the rights and services granted to disabled people.(ÖZİDA 2008, my translation).

¹⁵“The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”(UN, 2006:4).

social support line, provided facilities to students, EKPSS, other discounts and exemptions provided for disabled, conveniences provided to disabled students in university exam etc. The procedures to be performed in order to benefit from facilities such as health services, disabled care services, special education services, employment as public servants and workers, tax exemptions, social aids(sosyal yardımlar; engelli aylığı, muhtaç aylığı, evde bakım desteği) exemptions provided in the purchase of motor vehicles etc. are also explained in the guide(EYHGM, 2019).

As the participants mentioned during the interviews, the implementations written in the guide are very important in terms of facilitating the lives of people with disabilities. Semiha, for instance, stated that she educated in primary school in a public boarding school for the visually impaired, her family received disability care salary from the state during high school, and now she was working as a public employee at a high school library. Semiha said,“I had no expense to my father.” Likewise, all participants, except those whose parents were public personnel, reported that they were benefited from the monetary rights under the heading of social aid(sosyal yardımlar).

The language of the guide’s text is a kind of mixture of theory and practice. The “rights” have been written while the theoretical information were given such as legal rights. But when it comes closer to practice, expression of “the provided facilities” have become prominent. For example, the salary, which is a legal right, is explained under the title of *Sosyal Yardımlar* (Social Assistance/aids) (EYHGM, 2019:53). It is needed to underline here that policy makers and law enforcement personnel are also members of the society. Therefore the society’s perception about disability naturally shows itself on rulers’ implementations. In other saying, the help-only approach also manifests itself at the public institutions’ implementations.

As it is written in the Guide, urban transportation is free of charge for the disabled and their companions. This right was used by all of the participants. And, it would not be wrong to say that free transportation is the most known monetary right of disabled in the society. The thoughts on this topic, most exemplified by participants on any subject, show concretely how the help-only approach extends to state practices. Participants generally make mentioned of free transportation as an example of positive things done. Yet, they also talked about the difficulties in implementing this right as an example to explain the problems they experienced. Meltem, for instance, defined it as “discrimination”. She explained what she meant as follows:

I don't like these(free transportation, free ticket for disabled etc.) at all, it's discrimination, it's not useful, it can be discounted, but it's completely free, it sets us apart from other people. For example, now there is no difference between the disabled and the elderly, or to the martyr's family. If it is to be done, it should be done differently for everyone, different for the elderly and different for the disabled. It is sketchy, everything is done incompletely. I don't know why this is done at all. Supposedly it looks like the disabled are being helped. I don't like it, but everyone is grateful and happy. This is something that strengthens the perception of “disabled cannot do”.

From time to time, visible positive discrimination applications were discussed at ODED. As well as welcoming them positively, deficiencies were also emphasized. In these conversations, it has often been said that these practices make distinction those with disabilities from those others, as Meltem said. It was also mentioned that, these were just for show, and therefore their content was deficit, so they could not produce permanent solutions. Şule mentioned about one of her experience in a bus and emphasized the problematic of general approach;

Once on the bus, an old lady said to me, “Are you not ashamed to use a cane and take the bus for free?”. I stuttered and had to say that “but I am blind”. She was very angry with me and said something like “so why did you make makeup”. This was the first but there are always people who ask whether I really cannot see or something. In general, when people come eye to eye and notice later when I don't react, they say “I'm sorry, I'm sorry”. I am answering “no need to apologize”... The state should distribute all rights equally, and this equality is not that kind of equality, which gives everyone the same thing, because everyone's needs are different. Transport for instance, rather than making the train or bus free, have a braille map in the terminal, or make an app for visually disabled people.

The mentality of people about the disabled was also one of the most discussed issues. The assumption of “disabled person who only could be helped is inevitably dependent someone else” might be the most conveyed reason as the source of the mentioned problems that participants faced with. Melek;

There is such a thing in both government and the visually impaired, having someone with them instead of letting them do something on their own. For example, they give you a free transport card, but they also give it to your companion... Transportation to me and my companion is free, forget about that I am working or other things I achieved, there is a disregard, the mentality of “you cannot do it alone, have someone with you” mentality, no matter how old you are.

Here, there is noticeable similarity between the approach of the state and the person on the street, who with the intention of helping, disorienting blind people by grasping their arms without asking. The implementation of the right-based treatments that basically needed to facilitate the lives of disabled people leads negative consequences. It is not because those proceedings are not necessities but as the result of their inefficient and deficit practices.

Helping people with disabilities, which is a communal accepted norm, is a common response to disability in social life. The existing state of helping to people with disabilities in the society derives its source largely from the presupposition of “cannot do anyway”(nasılsa yapamaz). When this is the presumption what can be done to improve the disadvantaged position of life caused by an impairment, naturally would not go beyond providing temporary convenience. The reflections of this situation on social life, namely in practice, are manifested in every activity (or inactivity) related to disability by those who all are members of the society. Therefore, the perspective which I might simply conceptualized as the help-only approach, prevails in the context of disabled people. Based on the experience of visually disabled people, the research reveals that help-only approach has been internalized and is put into practice by the disabled, their families, people in their immediate circle, person on the street, and those who operate public regulations.

CHAPTER 5

THE CONSTRUCTION OF DISABLED AS NEEDY AND INVISIBLE

The term invisibility generally used in the frame of the invisible disabilities which are not seen on a person's body or behavior, like intellectual impairments. But in this thesis, the term is not used in this context. Invisibility here indicates both not being in social life although it exists, and being ignored and not recognized by the society. Invisibility of disabled people refers here both its embodied meaning and its metaphorical meaning. That is, disabled people are not being physically present in public life at the rate of their existence, therefore not being seen by the people. Eventually, the experiences of people with disabilities cannot be a part of the society. At the same time, they are seen not as they really are, but within the framework of assumptions about disabled people, so they are underestimated and not recognized by the society.

Invisibility is a multidimensional category in society. Invisibility of a group of people can be emerged as the result of very different reasons. At the end, all reasons can be intertwined in each other in social life. James Charlton(2000) emphasizes in his pioneering book *Nothing About Us Without Us : Disability Oppression and Empowerment* that, people with disabilities are invisible and anonymous. He argues that, there are three major reasons for this phenomenon and although the consequences are experienced differently depending on political-economic and sociocultural circumstances, this is the case throughout the world. To Charlton those three major reasons are;

People with disabilities are often abandoned, hidden, and shunned by their own families and communities; segregation and inaccessibility have prevented people with disabilities from conducting fully public lives; extraordinary sociocultural stigmas have been brought to bear on those who have disabilities that are not readily apparent, so that they tend to conceal these disabilities from others(2000:84).

Carlton also concludes that, two things have come up with the invisibility issue. According to this, the perception that disabled people are seen outside at a higher rate than a decade ago is correct, but disabled people who go to school, shop, marry, go to parties, play sports and go for a walk do not increase at the same rate.

Carlton(2000) writes in his book that one of the most common reactions to disabled people is that the waiter asks what s/he will eat, not to the person with the disability, but the person accompanying her/him. Similarly, Şule defined the invisibility as, "It is waiter's ask to sighted person who is with me what I want to drink". Most of the participants, all young adults, frequently spoke of

similar behaviors they were exposed to, namely being treated as if they were not there or as if they are not an individual by herself/himself. “People behave us as if we are little kids”, they said. When the general attitude summarized with these sentences is combined with accessibility issues, they frequently stated that, they refrain from being involved in social life. Therefore, the embodied meaning and metaphorical meaning of invisibility would be thought as if different issues, but actually they are not in the context of the lives of people with disabilities

Semiha and Şule, who were completely blind persons, reveal with their lives that they were as self-sufficient individuals as their sighted peers. They took special training to improve their independent movement and daily life necessities. They developed their self-care skills in the boarding school for the blind, and developed their independent movement skills when needed, although it was not at an early age and required personal courage and effort. In addition, the assistive technology contributes significantly to their activities by eliminating bodily obstacles of their visual impairments. They passed the university entrance exam with the appropriate examination¹⁶ and score arrangements¹⁷ for visually disabled students and received university education. And, they were working at public institutions by the state’s positive discrimination support implementations. Besides, both of them were self-confident persons who were struggling with social barriers that assumed them as incapable individuals. So, why does this vicious circle continue? Why are disabled people perceived as just needy disabled who can be helped-only? The research reached especially two answers to those questions. First is, because people like Semiha and Şule are very few in number in the society. And, the other answer, according to the data gained from the participants’ experiences, is because people with disabilities are not seen as they really are.

The “few in number” written above means that, the rate of disabled people who received university education is 7%(Eurostat, 2018). And, as reported by EYHGM from 2011 Population and Housing Census, the labor force participation rate of the population with at least one disability is 35.4% for men, 12.5% for women, and 22.1% in total in Turkey(EYHGM, 2020). In addition, 60% of persons with basic activity difficulty (with sight, hearing, walking, communicating) aged 18 to 24 dropped out the school before completing secondary education or training (It is 40 % for non-disabled people)(UNESCO, 2017).

“They are not seen as they really are” means that, they are seen as only blinds who are assumed as “needy”. It is obvious that in a context of social components that interact and therefore constantly nurture each other, needy disabled perception related help-only approach can have a

¹⁶ Visually impaired candidates are exempt from questions that include visual data such as figures, graphics, tables, pictures, and questions that contain complex expressions in the university entrance exam. Readers and marker assistants are assigned to these candidates and they are allowed to take the exam in single halls. Additional time is given to the extent determined by the amount of exam questions and time(ÖSYM 2019).

¹⁷ A different examination result evaluation is applied to the disabled according to the university departments applied for and the type and degree of disability. Accordingly, the assessment of exam results, such as additional score, quota or low minimum score regulations, is only valid for students with the highest grades of high schools and vocational high school students as well as students with disabilities.(ÖSYM 2019)

number of causes at the source. However, here, within the limitations of this study, the findings will be specified and analyzed within the framework of the invisibility of the disabled.

Here it is necessary to distinguish between “the disability” and “the disabled people”. One of my arguments at the beginning of the study was that disability is invisible in the society representatively and physically. Because, as mentioned before, 12 % of the population(SIS, 2002) is disabled but we do not see them throughout the social life. We do not see disabled people physically, for example on the streets, in schools and in workplaces. Or, we are not familiar the representation of disability, for instance, in the media or in politics in proportion to their existence. But, as the study progressed, I have noticed that it is necessary to sort out the disability and people with disabilities to clarify the invisibility. Because, it would not be wrong to say that there is a kind of positive sensibility about “the impairment” within the society, and this attitude is shading to understand the social and cultural reasons of the invisibility of disabled persons in society. The conversations with participants within the interviews about the people's reactions to direct financial support of the state made me reach this conclusion in addition to my general observations.

There are three types of regular monetary state support related with people with disabilities. These are the disability salary, home care salary and neediness pension. One of those can be received depending on the requirements of those who request(EYHGM, 2019). They all popularly called as *engelli maaşı* (disabled salary). One of the interview questions was that “Do people ask you questions about monetary state support to disabled, how do they react?”. All participants said that, people often ask to them or to their families questions about it, most of them stated that, people’s reaction to direct financial supports was positive in general. In addition, all participants mentioned that, they were using their free urban transportation rights and some free and/or discounted intercity transportation rights for themselves and their companions. And, they stated that they have not received any negative reaction in this regard, as long as it was realized that they were visually impaired. Moreover, participants spoke that they encountered words about disabled salary such as, "If the state is giving then it should be taken, this is your right." Those who did not take any kinds of disabled salary was even told that “if I were you I would take it.” The reason for those expressions in society becomes clear in Alp's answer;

People ask, they say how much Turkish lira do you get as the disabled salary? I say, we don't get, the money is for care allowance. Then they say, why don't you get it, are you an idiot? I say, we are not idiot, but we are not unfair people... Everyone who asks is saying that I should take disabled salary from the state, because they see us as handicapped, needy, without money.

As an interim note; some participants stated that their families’ income was sufficient, so they never thought to get disability salary or home care pension for their impairment. In addition, some participants cannot legally apply for disability pension because their parents are civil servants. One participant said that, his family's income was low but he could not apply to disability salary because his father was a public employee. He added that, he is not a child anymore, so his own income should be taken into account rather than the income of the household. Another participant said that, she did

not have the right to apply for a disability salary, because she was receiving a pension left by her deceased father. Nine of the interviewees reported that they were already receiving monetary state support, or received over a period of their lives depending on their age or job status.¹⁸

Returning to our main subject, Semiha's response to the question about people's reaction of disabled salary was slightly different from the other participants. That is, one of the sources of the people's non-negative approach to those direct monetary supports was also hidden in her answer. Semiha said;

People immediately think about money because we are disabled. They usually hide their reactions, and just say "good". Those who are not in a good shape of income oppose this situation, I do see this. Then, I say to those "don't be a disabled", thereupon they say "you are right."

There was a general affirmation from the participants' circle about receiving direct financial support from the state due to their impairments. It can be concluded here from what has been explained by the participants that, this affirmation is based on the acceptance of disability as a "human tragedy". In this case, taking a salary from the state as the result of impairment is seen as a necessity based on the assumption of "needy disabled" rather than a citizenship right. Nevertheless, regardless from its source, it is not wrong to say that, there is a kind of positive sensitivity in the society regarding disability¹⁹.

In this context, it is useful to say that the perception of disability in society is a "consequence". From this point of view, it is not "invisibility of disability" but "invisibility of the disabled" that needs to be searched and analyzed. Because, in this way it is possible to clarify social and cultural reasons of this consequence in the society. In other saying, people's perspective of disability is sourced from the "needy disabled" assumption, in that case the reasons of invisibility of "the disabled" should be investigated. By this way the definition of invisibility made by participants can be explained in the frame of daily life of the disabled people.

5.1 To Be a Needy Disabled Through a White Cane

According to the participants, disability is associated with neediness in everyday life. In general, it is assumed that a disabled person is inevitably a needy person(muhtaç). As a concept in this section, neediness, in short, refers to the situation of being inability of taking care of oneself due to inability to be a self-sufficient person. Based on the experiences of people with visual disability, the help-only approach and needy disabled assumption in the society are both each other's source and

¹⁸ Number of old age and disability salary beneficiaries under Law No. 2022 is 1,272,038. It is 1.60 % of population.(data from 2015 and excluding neediness salary and home care salary)(Ministry of Family and Social Policies & the World Bank, 2017)

¹⁹ It should be noted here that when it comes to personal interests in private fields rather than the salary received from the state, the reactions of people to disability are a different issue that needs to be searched with separate and other data.

nurture. Because, the perception of “*yapamaz*”(the disabled cannot do) is like an inseparable duo along with the assumption of needy disabled. The help-only approach, examined in different contexts in previous chapter derives its source from this understanding. At the same time, help-only approach rebuild the needy disabled assumption. As stated earlier, disability is socially constructed. Therefore, the ongoing help-only approach also reconstruct the perception of the disabled as a needy person in the society. So much so that, as seen in Table 4, the thoughts of people that participants want to change about the visually impaired were people's pity for them and the perception of “*yapamaz*”(disabled cannot do).

Table 4: The Thoughts of People That Participants Want to Change About the Visually Disabled

	If you had a magic wand, what thoughts of people would you like to change about the visually impaired?
Alp	At first, pity. People feel pity for (disabled) because he cannot see. People sad about him, look at that, he cannot see, they say, it is reflected in their behavior also, they say 'I absolutely should help', insist (to help).
Murat	Pity... We are not complete, we are not solid. Therefore in their eyes, we are a little like a lower layer.
Yeşim	I wish they would perceive us like a normal person. I wish there was no negative difference.
Esra	If I were them, I would treat the disabled naturally. Pity is bad, degrading
Rıdvan	Some think about (disabled people) cannot do anything, I would like to change that
Mustafa	I'd like to change perceptions like 'poor fellow' 'what a pity'
Mehmet	The attitude. I would at least change people's attitude. Cause there are people who ignore or who don't help, as much as those who help
Elif	Pity, I guess. I don't think it's pitiful. Worrying could be, empathizing and to be sorry instead of feeling pity. They look down on disabled people, they pity for them. There are many things that I cannot do but there are also what we can do.
Neşe	I'd like to change 'these (disabled people) cannot do anything, let's help them'
Aydan	Actually i think they are not that bad towards disabled people. It can be said that, I would like to change the way things like 'cannot do' prevent disabled people, I would like to change prejudices. I mean, a visually impaired person may think that they cannot go anywhere alone, and some families may think that they cannot go to a place alone. Because of that, I wish such prejudices were thrown aside.
Erkan	I would change things like that 'they cannot' etc.
Melek	I don't know, from the very beginning I would try them to perceive blindness as a difference, and I would like to discourage these normalization efforts... There is an effort to normalize, like, let's make them see first, then everything else will improved. When you cannot provide that, they are acting like there's nothing else to do.
Şule	The only difference between us is not seeing, everything else is the same in general terms, and (a sightless person) has to go to work, could get education or not. A sightless person just cannot see, this should be normalized.
Semiha	The thoughts they believe we cannot do anything.
Meltem	The idea of 'useless'(person). He is also a human being, is useful for everything. I would like to change that idea to 'a disabled person is a normal human, can does everything'.

In this situation, as Bezmez and Yardımcı(2013) stated, most of the dominant discourses and practices in disability field are carried out through the understanding of "needy disabled people". I observed during the fieldwork that the acceptance of disability as a neediness in the society decreases disabled people's life quality. Because, since it is assumed that visually disabled people need inevitably others to be able to achieve any kinds of their requirements, all relevant activities (and inactivities) are carried out based on this understanding. The life quality of visually impaired decreases because,

concretely, for example the visually impaired refuse to use a white cane and the accessibility issue is “seemingly” taken into consideration as the result of needy disabled assumption in society.

In the research *Cultural Definitions Regarding Disabled Individuals within Turkey: Example of Ankara*, Burcu(2011) analyses how non-disabled individuals depict disabled persons, depending on their socio-demographic characteristics and reached four major cultural definitions regardless of gender. These are:

- pitied, needy of attention-help individuals
- unwanted individuals excluded from society
- inadequate, unsuccessful individuals
- individuals who are struggling, defending their rights(p.51,my translation)

The last one reminds the picture some participants draw while describing themselves or their goals in life. Additionally, some participants mentioned that people appreciate them for their school achievements or when they were seen walking on the street on their own. The first three depictions were almost same as the the participants' portrayal of how the society perceives them.

Therefore, when the help-only approach is the starting point, effective and efficient results cannot be obtained in improving the disadvantaged position of disabled people in society. Namely, it is possible to learn the necessary techniques that are essential for independent movement, if desired, in special education centers. However, the importance of independent movement is push into back by the disabled people and their families. The issue of accessibility is disregarded in general. Public institutions, similar to families' approach to their children with disabilities, evaluate the disabled person not as an independent individual but with her/his family and perform their implementations within this framework. When all those, which necessary for the self-sufficiency of the disabled, are not effective, the needy disabled assumption, that even the disabled person believes in one point, is built and reconstructed in social life. One of the most concrete examples of the construction of the needy disabled assumption in the society will be the approach to the white cane, which is of great importance for the independent life of the visually impaired, and the issue of accessibility necessary for its effective use.

Accessibility is a term which indicates the individual's probability to participate to an environment to the extent of disabled person's desire in disability fields. Therefore, those environments where formed in a way to ensure participation are defined as accessible environments. Accessibility is discussed in any environment like, in communication systems, information technology, education, employment, public transportation and so on. One of the important point is that, accessibility is not a static phenomenon, it is interactive(Encyclopedia of Disability, 2006:9-19). In this sense, the only requirement is not only the accessible, physical environments such as sidewalks, means of transport or any other wide and closed places, but also access to the training of independent movement skills for visually disable people.

As it is explained in the previous sections, independent movement skills are essential in visually impaired people's life. Because, it basically refers that, people with visual disability can move around safely by their own without in need of any others. For this, it would enough to learn special techniques that will provide safe and trouble-free mobility and to acquire a white cane.

In daily life, for the people with visual disability, the term independent movement is usually mentioned together with the usage of white cane. Because, as Altunay-Arslantekin(2015:45) quotes;

The cane as the basic mobility tool for the visually impaired provides auditory, tactile and kinesthetic feedback(Glanzman & Ducret; Leong). Canes can give information about the surface properties(roughness breaks on the surface)(Rodgers & Wall Emerson). Cane use is one the necessary skills of orientation and mobility instruction for the visually impaired to predict what is ahead along with the obstacles and surface changes(eg. steps or sidewalks) (Sauerburger & Bourquin)

A white cane is a light and thin stick tool that visually impaired people hold in front of their body while walking, and slightly touch the ground. If there is a red strips or tape on the white cane it indicates that, the holder is a person with deaf-blindness. Tactile and sound stimuli from the cane enable its visually impaired user to recognize orientation marks and also obstacles in their path. It is white in color to allow those them around can notice and take appropriate care the user as visually impaired(Altı Nokta Körler Vakfı, 2016; Kösele, 2021).

Participants state that, if requested, training on the use of white canes was provided in special education centers and related associations for the visually disabled. The fees for these courses were paid by the state, like all courses in these special education centers. At the same time, the white cane training can be obtained free of charge by the relevant associations. Therefore, owning a white cane is very easy and does not have a financial burden. Because, participants who use white cane said that, especially relevant associations and foundations provide free white canes to visually impaired people at regular intervals when requested.

Sightless people, if they have, are defining themselves as "I have independent movement"(bağımsız hareketim var). Those who actively use white canes among the participants, mostly met with it at primary school, but even so, learned to use it efficiently from special education centers, institutions, their friends and on their own. The white cane is the first and, apparently, simplest and practical way to achieve independent movement, except for those who come up with personal solutions with time and experiences to achieve the independence due to the wide variety of types of visual impairment.

However, when it comes to getting involved in social life, using white cane is not that simple or practical. That is, some young sightless people do not want to be pitied in the society because of their impairment, and somehow they believe that carrying a white cane will cause it. For this reason, Yeşim and Esra refused this solution even though they knew that it would make their daily life much easier. Yeşim would rather be outside than at home, but needed her younger sister for going from place to place and said about that;

Actually, I like to spend time outside, but, since I cannot go somewhere alone... I generally love to spend time outside if my sister or someone else is available. I have to use a cane normally, I know the technique of using it, they have taught me to use it, but I do not use. It feels like, the cane is a burden to me, or everyone on the street is watching me. Maybe they say, "oh, what a pity, she's using a cane", I don't want it, I feel depressed... I should actually use it because we would separate with my sister, she wants to go another city for the university, but I want to stay in Ankara, then I will not be able to go anywhere alone... I need to get used to it.

Esra needed her mother for arriving from place to place. She preferred to be in home than outside and told about the issue as;

I am more comfortable at home, because I don't go out alone. I go out with my mother everywhere. Not always, sometimes I use a cane ... (Cane) helps us to follow the paths, to see if there is something in front of us, trees or something... I find it difficult to walk from the school bus to the door of the school, because it does not enter the street, thanks to the security guards they help me, because I cannot find the stairs. After the stairs, I take care of myself. My German teacher taught that to me. He took me around the school building in one lesson, said you will go like this and so on and so on, because he realized that I did not go by myself, I did not even deign to walk, I always went with my friends, I did not want to go myself, I was afraid, it was a crowded environment. I did not even use a cane. I didn't use it for two years (after I started inclusive school). I don't know, I worried what people would think of me, actually there were no malicious people but I was afraid anyway, whether if people realize that I was a blind, because only my class knew, nobody else in the school knew that. Then the teacher asked me to bring my cane, and he got angry with me when there is no cane. I also agreed with him, because he was a teacher I loved very much. Now, I feel very strange when there is no cane anymore in the school building, I notice my front, other pupils understand that I am visually impaired, it is comfortable for me. I don't know why I was hesitant before... I saw it as a burden... Okay, even now, I see it that way, actually. Okay, it provides me my freedom, but I still see it as a burden! The cane is a burden to me.

As it is understood from these two examples, it is not desired to be used, despite being aware of the comfort that a white cane would provide. This must have something to do with the meaning attributed to the white cane. Esra defined what she meant by saying white cane was a burden to her as; "Not in terms of weight, but... I cannot express.. but, for example, those who can see can go comfortably, we have to pay attention to a cane in our hands." Actually, I frequently heard that "white cane is a burden to me"(baston bana bir yük). So, I asked its meaning to others who constantly use white cane; Semiha;

Those who are ashamed of their disability and those who do not accept it often say that. They are refrain from being a blind and do not want to go out with the cane. I am not like that, I do not know why they do it like that, they say I can see but they do not. You are visually impaired, accept this! I don't know why they do not accept that.

Meltem;

I think they do not mean as load, they are ashamed, so that it will not be understood that they are visually impaired. I have a friend who needs a cane a hundred percent, but she doesn't use it. She is going everywhere with her family. She goes to school with her family, she moves only in her house. However, it is understood that she is visually impaired even though she does not use a cane. I told her that too. She thinks that I am stupid because I am using a cane. Why should I be stupid, I take care of myself. This is how I brought one of my friends to life by convincing her to use a cane. She thanks me so much right now. Sightless people

are ashamed because the public puts the disabled as the person who cannot do anything. They don't want people think like that about themselves either. I have a friend, her husband and herself are visually impaired. Her husband can see better; he doesn't need a cane except in the evening, but my friend always needs a cane. After getting married, she never goes out without her husband, so as not to use a cane." Could they be afraid of harassment? No, if she uses a cane, she would not hit anyone, nor would she be harassed. Some families never go anywhere with their children because they are ashamed of them. I had such a hard time with my brother, he wouldn't want to go anywhere with me, he would be ashamed of me. I have never be ashamed of myself, but I was sorry for his attitude.

In a sense, people who know to use and are also aware of the need to use the white cane are not prefer it at the expense of their independence to avoid confronting stigma. Stigma is Canadian sociologist Goffman's well-known conceptualization which is also used in disability studies (Kasnitz & Shuttleworth, 2001; Reid-Cunningham, 2009; Rapp & Ginsburg, 2012). Goffman (1963) explains stigma in the frame of, "an attribute that is deeply discrediting" (p.3), as well as "a special kind of relationship between attribute and stereotype" (p.4), and as the final "an undesired differentness" (p.5) from expectations of "normals" (p.5). In anthropology stigma is detailed by Joan Ablon in the course of her 25 years ethnographic studies with people with impairing genetic conditions, dwarfs, and people with osteogenesis imperfecta. Ablon focused on social exclusion as the result of bodily differences as well as her informants' perception and reactions to their stigmatized status in community (Shuttleworth and Kasnitz, 2004).

Stigma, in short, refers to the state of being exposed to negative stereotypes which sourced by the assumption of the person is different for a reason. In disability literature, stereotyping and labeling are mostly being considered under the subject of stigma in so much that, these concepts are written in *Encyclopedia of Disability* by directing the reader to the subject of stigma (Albrecht, general ed., 2006, xi-xvii/ix-xv). In the context of the thesis, those sightless people's above mentioned behavior of refusing to use a white cane can be explained as avoidance response from being stigmatized by the society as a "needy" person.

Besides those who refused to use it even though aware of the advantages of the white cane as well as has been thought how to use it, some of participants stated that they were not aware of the comfort and ease provided by the white cane until they reached a certain age. They were also not aware for a long period of their lives that they could use it actively. Melek conveyed this situation, which is actually a clue to the general lack of knowledge about visual disability in the society. Melek's sense of vision decreased from 50 percent to 5 percent as she got older. She started attending the school for the visually impaired in secondary school, received inclusive education in high school. But, she had to explore the white cane and how to use it by her own. Melek;

People who have developed self-esteem at school can make friends directly, I did not have this opportunity. Nobody told me to take that cane and walk, everyone told me to walk with my friends. For example, when I was in the 10th grade, I wanted to go to my 9th grade friends, classrooms were at the same corridor, it was not too far, but I could not go there, I was very afraid of hitting people, of what people would think of me. I went to the school guidance counselor, I told him, I said I feel very bad, he said 'I don't see you like that, only

you think so', and that's all, he didn't care.... I used to think it was miraculous, when I lost the first sight, I mean, my friends or others would walk on their own with a white cane, I found it miraculous, it seemed so complicated to me. Where to turn, what to do, cars or everything on the streets, I thought it would be very dangerous. But, you get used to it somehow. At first I was walking with my friends, then I started to walk on my own... I took the independent movement lesson in special education, but walking outside is very different from when the teacher demonstrating the independent movement in a closed space.

Low vision Melek's situation is a concrete example of social ignorance about visual disability. She attended a school for the blind in middle school, but nothing was done to teach her to use a cane at school, probably because by then her peers knew how to use a cane. Despite the inclusive education in high school, nothing seems to be known about visual impairment. First she had to discover that she could use a white cane, and then she learned to use a white cane on her own with the support of her friends. This meant that, using a cane might still have been “miraculous” for her and “dangerous” to be outside. In fact, Melek was one of the participants who talked most about her unhappiness in her school years and the time she lost. Şule was, another participant who talked about unhappiness. But, contrary to Melek, Şule did not want to use a white cane, because she thought she did not need it. However, later, had decided that she needed to act independently in order to receive the education that she could be happy with;

When I was in high school, I did not use a cane, I was going everywhere as if I was someone sighted. Even the school bus was entering the school to pick me up... I was obliged to study at a university in my birthplace but I was unhappy there. Contrary to this, I agreed with my family that they didn't want to send me to another city, because I did not have an independent movement. Then, I said to myself that I have to learn how to use a white cane. I already had a cane at home. First, I started to carry it always with me, but my parents were still picking me up from school. Then I decided one day and I didn't call them to pick me and I went home all alone. It was very difficult, but I got home after asking people on the way... Then I transferred to Hacettepe. I am going very well to places I know right now. I have to ask in places I don't know, just like sighted people, they also ask. There are problems with the address directions though, they need to describe it clockwise, but of course people do not know.

Based on the experiences of the participants so far, reasons for not using a white cane or start using it at a late age can be listed as, hesitating to be stigmatized, not being aware of the fact that they could use a white cane, and not knowing the opportunities it can provide.

Another reason for not using white canes can be expressed as environmental barriers. Some participants, like Rıdvan, said that they do not use white canes because they believe that independent movement of the visually impaired was not possible in a big city. The family of 19-year-old Rıdvan moved from a village to Ankara for his education when he reached primary school age. He went to primary and secondary school in the school for the visually disabled, and received inclusive education in high school. Rıdvan reported that, there were independent movement and daily living courses as elective lessons at the school for the visually disabled pupils for 8 years. But, he took only one semester each of those courses. He said its reason as; “Because, my father said 'concentrate on the music lesson, at least you may play an instrument'. But I couldn't do it at all, so I quit it either.” One of

the most successful students in the exams at ODED was Rıdvan. However, he needed someone else to prepare a hot drink or prepare his meal or to go somewhere outside. And, he would rather be at home than be outside;

Ankara is not a place to live in terms of independent movement. I do not use white cane, it is very crowded, and the roads are narrow and crowded. That's why I'm thinking of going back to my birthplace. The streets are wide there, the streets are not that crowded... Independent movement works there, I would use a cane there, in addition, the people at there are, more like... I mean, Ankara is a very fast city, life is very fast. Places like my city is not like that. If you miss a bus here in Ankara, you have to run constantly.

Rıdvan mentioned before that, he had spent his summers in his hometown, but he did not use a white cane there either, he was always with members of his family. In order for the use of white canes to become practical, its techniques must be learned. In addition, according to the statements of other participants, in order for the use of white canes to become efficient, if it is started to be used after childhood, one should practice on his own everywhere, she or he walks around and have to make it a routine. According to Mustafa's experience, it took at least one year for the use of white cane to become a routine. He explained why he started to use white cane late as follows;

Families, about going out, I mean, God bless them, there is no problem now, but I had a lot of trouble with my family before, just because they were afraid if something bad would happen when I went out on my own. The family will resist at first, but it ends with the person oneself, I think if he proves something, it will be alright. I started using a white cane when I was 16-17 years old. We don't go anywhere in elementary school anyway, you know, school to home. One day I went out without my family, thanks to a few of my visually impaired elder bros, we had a period of one year to go out with them, and then I got used to it slowly. I came here myself from Etimesgut, by walking plus two buses... I took a friend out too. He previously could see a little, then he slowly lost his sight in degree, and completely lost it after secondary school. He still don't accept it but not as much as before, I left him alone for a day to encourage and then he started to go out on his own.

Those all above are like a micro summary of the general reservations about using white canes. First of all, awareness of the use of white canes is required by the families as well as the visually disabled people. When visually disabled are noticed, they hesitate to be perceived as needy individuals in the society. In other saying, they avoid to be labeled as needy disabled by people, since being disabled in society is perceived as being directly "miserable". Therefore, they are trying to hide their impairments by not using white canes. Families resist their children for going out alone with the worry that if something bad happens. In addition, they may not be aware of the importance of learning the techniques necessary for independent movement in line with the presumption that their children are incapable in any case because they are impaired. In addition, for those visually impaired who reach a certain age, it is understood that, besides being stigmatized, environmental barriers as well as social unawareness are also the obstacles preventing them from using white canes.

The efficiency of the use of white cane depends partly on accessible environment. In this case, in addition to the necessity of orderly spaces and flows of traffic, it partly depends on the effectiveness of tactile paths on sidewalks and the public knowing how to behave when they see someone with a

white cane in traffic. The experiences of the participants demonstrate that, people have extremely insufficient knowledge on this subject both in terms of tactile paths and traffic problems. Neşe with low-vision, for instance, has had very worrying experiences in this regard;

I do not say anything, because I don't want people to be upset for me, I'm not telling my parents or friends things that happened in the evening or when I go to school, for not to make them worried. I'm not telling them that I fell, or cars crashed. How many times cars have been hit me so far I don't remember. Nobody should be sad for me.

Neşe was not using a white cane. She also was thinking that, her use of a white cane, which would expected to make others around to be more careful with her, cannot be a solution for providing her safety;

Because, they crush the white cane too. Most of the visually impaired's white canes are always crushed, if you look carefully you will see. My friends' canes are always crooked. Motorcycles do this, the visually impaired friend is jump to road, the car comes suddenly, you know Kızılay. Originally when s/he lifts the cane, the cars have to stop.

One evening, we went to Sıhhiye from Kızılay with Neşe and Alp for shopping. This region is in the center of Ankara, at the connection point of buses and subway, with lots of shops and workplaces, so there is a dense traffic and crowd. We were walking fast because we were in a hurry. Alp's folded white cane, which he always carried, was with him. When we were close to a very crowded spot, Alp opened his cane with a quick and practical movement to open the way ahead. Those people around who recognized the cane, pulled aside without slowing down and continued on their way. Neşe mostly got on Alp's or my arm. She stumbled for once or twice. However, since she knew the way very well, she was the one who guided us by saying, "Let's go from this side, we will arrive faster" and so on. We crossed the streets twice. While passing through the red lights, the "cross now" announcement from the audio system could be heard if listened carefully. The road we walked took approximately twenty minutes. During this time, Alp constantly showed the cars parked on the tactile pathways. In addition, we noticed the edges of some of these tactile surfaces that have been removed.

I have observed that, students using white canes at ODED, sometimes help each other to repair their canes. When they came from the street, the tips or the body of their white canes were curled. They once found a temporary solution to a broken cane with glue tape. During our conversations, it was mentioned that, people stepped on the cane while walking on the road, or a vehicle passed over the cane while crossing the street.

It was also frequently mentioned that, tactile pathways(yellow line) slide in snow or rain, and care should be taken as there was a risk of getting stuck on broken, raised ends or bent. Students with low vision mentioned that, a person who was completely blind has to use the tactile pathways for a safe walking. However, they did not prefer to use it as much as possible because of the risks of getting stuck.

Seemingly, a visually impaired who is using a white cane, can comfortably go from Kızılay to Sıhhiye or from his home to this region by using guide-ways, audible traffic lights and the public approach to them. As a matter of fact, it is not wrong to say that, people using white canes are more common in this location than in other regions of Ankara. However, the statements of the participants show that this is not the case when it comes to practice. During the interview, Alp particularly talked about his conflicts with those who parked their cars on tactile pathways;

Our people is insensitive, forgets. I was fighting a lot of people, quite a fight. They park on the yellow line(tactile pathways). I am able to see in the daytime but some of my friends are totally blind. White canes are broken because of those cars... Last week, a woman washing her car above the yellow line, said 5 minutes later she gonna pull the car. I checked out 5 minutes later, it was not...

He told two more stories like that, and could continue to tell, because he said that he was always experiencing similar events. Although every warned person apologized at the end of those conflicts, he was not hopeful; “Nothing changes, one day they don't park there, two days later they park again... The solution is, need to change the brains. Maybe, the grandchildren of my grandchildren can see that things have changed.” This issue has often been mentioned throughout the research. Mustafa, for instance, who was a volunteer at a non-governmental organization at his neighborhood, told that they struggle to have accessible environmental elements in his district in a way to cover all types of disabilities. And, he said; “Yellow lines are good things, but their deficiencies are more, therefore it becomes trouble, deficiencies like broken off, disconnected lines or parked cars on them.”

The fact that tactile paths are constantly violated by sighted people and that they are not made in a way the visually impaired can safely use are, very concrete examples of inefficient results in solving accessibility problems. It can be thought that this is based on ignorance as Alp said similar to the general opinion. However, for example, it has been realized by the public that these paths are necessary and should be made at streets, or subways or some other closed wide places. As the result, investments have been made for yellow tactile paths. Likewise, people who parked on these paths were always admitting their mistakes and apologized when they were warned. Therefore, it is necessary not to be overlooked that there may be some other problems which caused the situation more than simply just ignorance or insensitivity. In other words, it should be considered that, there may be a stronger reason which also cause such ignorance and insensitivity.

Then why? Since disability is a very broad and interdisciplinary subject, many answers can be given to this question. The main axis of this thesis requires a research on cultural and social reasons through daily life. In this context, the main answer is that, most of theoretical solutions to the problems of disabled people are inefficient when it comes to implementation. The source of this inefficiency comes from the assumption that, disability is identified with neediness due to its presumed nature of the impairment, so it is accepted that, what can be done in this regard is limited in every way. In this case, the quality of the guideways or the requirement that the guide line should be clear can easily be overlooked or become of secondary importance.

After all, it is supposed that, the disabled cannot do it anyway then the only thing that can be done is to help them. That is, the family cannot acknowledge the necessity of independent movement by thinking that “I will always help anyway”. The citizen, who cannot realize the inconvenience of parking on the guideways, enters the arm of the visually impaired person without even need to ask. When the tactile pathways are planned with the perspective of the needy disabled at the bottom, what material should be used in the construction of tactile paths is overlooked. Therefore, this environmental accessibility solution, which should facilitate daily lives of the visually impaired, turns into a new obstacle as it is slippery. Hence, the help-only approach leading the needy disabled assumption of the society lie at the root of the issue.

This same understanding lies under the fact that visually impaired people do not use white canes in order not to feel like needy people. It causes some sightless persons to be unaware of the white cane and its effects on independent living until they are old enough to discover it for themselves and realize its importance. The help-only approach, in general, causes to ignore real needs of a disabled like using white canes to involve social life. When accessibility issues are added to all of these, the practicality and importance of using a white cane becomes invisible. Ultimately, persons with visually impaired are not using white cane, so they move with the help of someone continuously, and thus the needy disabled perception is reinforced within people with disabilities as well as in the society.

5.2 Invisibility of Disabled People

People with disabilities are also members of the society they live in, bearing the social and cultural characteristics and thus reflecting them. Based on this, it is necessary to analyze the statements of the participants from two sides. The first is, to evaluate the experiences of the participants as the experiences of the disadvantaged people in the society because they are young and disabled. The other is, to analyze the participants' perceptions, attitudes and evaluations of their experiences and also society, taking into account that they are members of the society.

The participants were agree that visually impaired (and all disabled people) were invisible in society. For them, meaning of invisibility as a disabled in society were, not being known, being treated as not exist, unheeded, disregarded, being neglected, not valued, not respected, not seen and not heard. It was stated in previous sections that, the term invisibility expresses to both its embodied meaning and its metaphorical meaning. Therefore, invisibility of the disabled refers to, in concretely, disabled people do not take part physically in public life, so they are not seen, and in metaphorically, disabled people are unrecognized and undervalued by the society.

Almost all of the participants, including those who attended to preliminary studies, stated that “the society does not know what disability is”. Also, according to them, people cannot comprehend

the life of a disabled person without living it. To them, disability was a situation which could be understood in real only by being disabled or (maybe) by living with a disabled person. That is, as Semiha said "Not known of course. It is not known before you get into it, you have to be sightless to know." Alp said; "If there is no disabled person around you, you cannot know. How do you know something you haven't seen?" In addition, many of them emphasized that, their families were also unaware of the disability before they were born or were impaired. Murat said, for instance;

My mother always says that, we were ignorant (about visual disability), we didn't know before we befall, we didn't realize it. For instance, when they saw a blind guy walking alone, they had ran after him and shouted as; the blind, the blind is coming!.

Melek also said that; "My elder sister tells that, when I was born, they did not know anything about (the visual impairment) then, so they had a great anxiety for the future." The participants also underlined that, if there was no any awareness in the society about disability, it was also not possible to have information about it. As Melek said; "No, it is not known, nor is it curious. If I am not visually impaired, if there is not such a person around me, or if there is no awareness, I would not look at it, because such a thing does not come to my mind.", and Erkan said; "It is not known, that is the issue... It is not known because it is not experienced and awareness studies are not conducted."

The sentence that was frequently repeated both in the in-depth interviews and in the conversations was *yaşamayan bilmez* (the one who does not live, does not know) as Rıdvan said; "People don't know disabled people's life, there is a proverb "one who does not live does not know". People cannot know how to behave (to a disabled) because they are not living (as a disabled), they only can know how to behave if they live (as a disabled)." Likewise, Yeşim said that; "No, not known. Because whoever does not live does not know, why should anyone know?. Maybe you wouldn't know if you weren't familiar with us either."

According to the participants, the fact that "disability is unknown" is one of the reasons for the prejudiced approach to the disabled. It is needed to note here that, *yaşamayan bilmez* is mostly used to define a complex situation in Turkish. It also mostly indicates a painful, personal circumstance. Although it is a personal circumstance, the study is focused on the complex situation part of the term. Because, this term and its used insistently by the participants, in the context of any problems they were faced with, gives an important clue about society's understanding about disabled people and also the disability.

Viewing the clue from an angle, if "the one who does not live, does not know" then what could be the reactions of that "one" to a disabled person? Because, the fact that disabled people are not known at this rate is also show us a sign that, the society does not aware of disability. That much lack of knowledge and unawareness about disability, inevitably causes personal interpretations about being disabled framed with stereotypes of the community. The participants' narratives explained both the facts that people do not know and the importance of knowing, pointing to situations that would change if they knew;

Şule;

My grandmother knows blindness as something terrible. When my leg was broken, she said, that, you were already a half my child, you are more half now. People who have never seen blind persons around them felt themselves very dreadful when they imagine themselves blind, and they assumed that it is extraordinarily difficult to be blind... I was invited to a stigma lesson in Hacettepe, things I told there was very interesting for them. I understood from there that people don't know and if they actually know, a lot would change.

Melek;

Families think that their children cannot do anything, that is, they cannot see then they cannot do anything because they are sightless. Their sightless children believe they can and they are trying to prove, they are constantly trying to prove themselves, which causes serious stress... I said to my sister, I said you are blowing out of proportion because you are out of to be sightless. Stop worrying about how to eat, etc. My sister does not have that much trouble anymore, but I know that from about the problems mentioned in that Facebook group I said before... Recently I was on the bus, an old lady came to me and told me to get up, someone else intervened and said her that I am a sightless person. The lady said, but she has a phone, how can she use the phone if she is blind?.

What the participants told about the subject concretely exemplifies the conclusion here. This means that people assume they are blind and then attribute things they think they cannot do to those who have spent their lives blind. And it seems that the number of people who do this is too large to be underestimated in society. On the other hand, Meltem talked about the problems she faced, as nothing is known about those with low vision. In fact, this situation is one of the consequences of the lack of awareness and also problematic perception about visually disabled persons. Meltem said;

When it is said the visually impaired, it is understood that a person cannot see at all in the society. Therefore, if you are able to see even so little, our people are thinking that they are deceived. They do not know what is low vision, they think we all are completely blind. I was the only disabled person in my high school, since our people do not know, I was assumed as to be privileged or something like that. It wouldn't be a problem if I were totally blind. Only after 10th grade my teachers and friends got to know me and then began to trust me.

Viewing the clue from another angle, the *yasamayan bilmez* phrase is participants' experience, but at the same time it is their opinion as members of the society. They were invariably use this phrase related with disadvantaged position in the society as much as bodily problems due to impairment. That is a data about the society's disability perception, which is assumed disability as a personal tragedy, not a socially constructed situation. Additionally, it was interesting to recognize that, this insist of using the sentence by the participants shows that, not only people with disabilities but also social construction phase of disability is invisible in the society.

After each topic of the interviews, the participants were also asked whether their similar experiences were valid for people with other types of disability and/or whether they had information about the situation of other types of disability in the relevant subject. Those questions were often left unanswered. When the answer was given, it was in the form of guessing or expressing an opinion. That means, participants did not have knowledge about other disability categories, if there was no any other disabled person in their families or close environments and relatives. It should also be noted that,

the answers given were expressed in the frame of difficulties and level of abilities. In other words, regardless of the subject, the answers given about people with other kinds of disabilities were verbalized via the level of “incapability”. In addition, it was interesting to observe during the interviews that, some of the participants surprised when they realized that they were not aware of people with other kinds of disabilities.

Both in the interviews and in our general conversations, the participants made comments about other types of disabled people similar to the society's judgment of them. Some of the opinions frequently stated by participants can be listed as follows;

- People think of pity (us), in my opinion we are not pitiful because our hands and feet are healthy, thank God, we are not crippled, only our eyes cannot see.
- Okay, of course, not able to do everything like the normals, but there are things they can do.
- I am a low vision but somehow I can do paperwork or something, but a total blind cannot.
- I am in a position better than hearing disabled. I am very sad about them, they are not able to communicate with others.
- Everyone can do something, more or less, even those with one arm can do something, even mentally disabled people able to do something.
- I don't know, but they somehow manage just like us.

As a result, the majority of the participants expressed their opinions about people with other disability categories by saying “I am empathizing” or “I am putting myself in their places”. Accordingly, orthopedic disability was the most difficult for some participants, while hearing impairment was the most difficult for others. For instance, to Aydan not being able to walk was the biggest impairment, because their life was unknown and what was done for them in terms of accessibility was very inadequate. But, to Erkan, orthopedically disabled people were the most unproblematic disability group regarding accessibility. On the other hand, to congenital visually disabled Rıdvan, the hardest thing in the world was to be blind later in life. And, for some, the real disability was being mentally handicapped.

As mentioned before, visually disabled people are also members of society that carry and therefore reflect the social characteristics and cultural codes of the society. In this context, lack of knowledge of the participants about other disability categories, also supports the opinions of theirs that, disability was not known in the society. This situation is one of the sources of the prejudice "the disabled cannot do in any way" in society. That is, for sure there were other types of disabled people that participants met in their lives. They described these other disabilities and disabled persons' lives based on their own personal experiences that accompany cultural stereotypes.

Most of the participants did not have information what other types of impairments were, their effects on people with disabilities, what the obstacles they face in all areas of social life and how they actually live their lives. Instead, their subjective beliefs, feelings and desires, often based on societal stereotypes of disability, have been articulated, and, in connection with this, the assumption of

incompetent persons again manifested itself. In other words, they had opinions about people with different types of disabilities and judgments that they reached by these opinions. This situation reminds rest of the society's problematic perception for visually disabled people that does not have information about, just like the prejudice of "needy disabled".

When analyzing this situation, it would be useful to explain the concepts of stereotype, prejudice and discrimination in the context of disability studies. It is difficult to say that these concepts, which seem to follow each other but are actually intertwined, have a widely accepted definitions. They are mostly subjects of discussions and studies with their interrelated contexts. For instance, "structural forms of discrimination" is identified as laws that prevent disabled people from marrying, attending school, owning land, or voting(Encyclopedia of Disability, 2006:387). On the other hand;

...discrimination can also be positive and have the restoration of equality as its goal. Positive discrimination can be effected by social assistance measures in cases with an extrinsic character(eg., income). It can be effected through authoritarian measures (which raises the question of personal freedoms) or finally by preferential measures(eg., employment quota policies that favor disabled workers). It can be conceived of as a compensatory measure and defended on the basis of distributive justice(Encyclopedia of Disability 2006:927).

Goodley(2011) defines social attitudes toward disabled people as "acts of political and cultural life" and put them all in the box of discrimination without making any distinction between stereotype and prejudice, or distinguish discrimination attitudes. He wrote in *Disability Studies - An Interdisciplinary Introduction(2011)* preface that;

Undoubtedly, societies subject people with impairments to discrimination. Disabled people have been hated, made exotic, pitied, patronized and ignored. Disability also evokes admiration, curiosity, fascination and sympathy. Disability studies respond to these acts of political and cultural life(p. XI).

Kasnitz and Shuttleworth(2001), on the other hand, put discrimination in the definition of disability;

Societies may or may not perceive impairments as resulting in functional limitations. These functional limitations may or may not be disabling dependent on culture and situational criteria including stigma and power. Disability exists when people experience discrimination on the basis of perceived functional limitations. A disability may or may not be a handicap, or handicapping, dependent on management of societal discrimination and internalized oppression, particularly infantilization and paternalism, and on cultural and situational views of cause and cure and of fate and fault(p.2).

In Encyclopedic of Disability(2006), the definitions of stereotype, prejudice and discrimination were not made with any entries or headings on their own, but depending on the context of interrelated headings or subtitles. This may be because, "prejudice and discrimination against persons with a disability has existed across the globe and throughout history"(p.1) and therefore no further explanation was needed for known concepts. Still, there is an explanation of those concepts in the Encyclopedia which also corresponds to my observations in the fieldwork;

...society has certain beliefs or stereotypes about people who are different. Pity, dependence, incompetence, and character weakness are some of commonly expressed stereotypes about

people with disabilities. Prejudice implies negative stereotypes, and discrimination is defined as a behavioral reaction of prejudice. Discrimination toward people with disabilities includes outright intentional exclusion or relegation to lesser services, jobs, or other opportunities. Formation of stereotypes and subsequent prejudice toward people with disabilities are often caused by misinformation or misconception(p.585).

Negative stereotypes and prejudices leading up to discrimination in public life are social obstacles experienced by disabled people around the world in general. In fact, it would not be wrong to say that, these are the basic concepts that turn a physical or mental disorder into a disability. Cultural differences reveal how these are experienced and even reproduced in daily life. The experiences conveyed in this research show that, disability is unknown in the society, and this is accompanied by misinformation and misconceptions about the disabled.

As it is understood that, to be different is one of the decisive keys point to the social attitudes toward disabled. When faced with things that they have not seen and were not aware of, people's reactions occur within the framework of stereotypes and prejudices. Hence, behaviors towards persons with disabilities, for which society has such a lack of knowledge, derive their source from the cultural stereotypes of society which mostly forms to prejudices. That is, in the society, it is essential to help the disabled individual, who is presumed to be in need, in terms of both religious and cultural codes and social behavior patterns. The situation of the people, whom the participants frequently complain about, not knowing how to help can be explained in this context. The act of helping which made regardless of whether it is wanted or not, with motivation of supposed neediness, inevitably causes a hierarchy between disabled people and non-disabled people. When a situation arises in which the disabled individual feels humiliated due to the hierarchy that has been formed, the issue is not stereotypes anymore but prejudices, even discrimination. So, when the source of the act of helping is prejudices, how to help is based on these prejudices, not disabled persons.

If we clarify the subject a little more, it is thought that, the disabled unable to do anything, primarily due to their perceived functional limitations. Since the socially created part of the disability is not visible in society, it is assumed that, what is essential is the act of momentarily help. In this case, the help is performed in the way that comes to mind first and after all what should be done goes no further than helping. Without realizing that disability is not only a bodily problem but also socially constructed, can, for instance, the importance of accessibility be understood? It is necessary to have information about the disabled for the act of asking whether the required is help only, or even how to provide the right help. It is needed to be aware in order to have information. And, it should be visible in order to be aware.

Here, the situation that the participants define as “insensitivity of the people” about the issues such as accessibility, if we exclude the unconcernedness, is actually related being unaware to some extent. On the other hand, considering participants’ convey especially between lines, another issue that needs to be examined here is that, the awareness within a certain extend is also problematic. That is, it would not be wrong to say that, there is a degree of sensitivity in the society about disability

when taking account disability salaries, EKPSS, people's attempt to help the disabled person either this or that way, and the like. However, the sensitivity is shaped around the "needy disabled" bias.

There are two situations here after all. First, as analyzed so far, there is a lack of information in society caused by not being aware of the lives of people with disabilities in general. Secondly, even if there is an awareness, it is mostly a kind of familiarity formed within the framework of "personal tragedies" which were assumed to be experienced by the impaired person. Because, there is an effort to create awareness in the society to some extent, but based on presumed inability, not through what disabled people actually do. In other words, misinformation and misconceptions take place on the stage in awareness-raising activities. One of the findings that makes concrete this inference is the concepts of week and day for the disabled people.

In Turkey, since 1992, every December 3rd is accepted as the International Day of Disabled Persons²⁰, and also May 10 - 16 is accepted as the Week of People with Disabilities²¹. In addition, different days have been adopted in order to draw attention to different types of disabilities and create awareness. October 15, for example, is White Cane Awareness and Safety Day. The goal of the day of December 3 is summarized at the related web page of Ministry of National Education as;

By organizing various events in our country, it is aimed to ensure equality of opportunity in areas such as education, health, working life and to respect differences, to create social awareness by drawing attention to the importance of access to technology and information as well as spatial access for these individuals(MEB, 2020, my translation).

These dates are announced and activities are organized every year throughout the country. The state institutions and municipalities give messages and publish public service advertisements. Commercial organizations and trademarks make special promotions for the disabled people about their products, and occasionally they give start to some social responsibility projects that are announced particularly on these days. Television channels take the disabled people into their programs on this occasion, a section is definitely reserved for this day in TV and radio news. Activities are organized in the schools for disabled people and rarely in other schools mostly which has special classes for intellectual disabled pupils. Besides, more institutional-scale activities are held in some of autonomous public institutions such as universities. Additionally, in the virtual world, politicians, celebrities, commercial firms, public institutions, disability related associations as well as ordinary people post and forward messages or video clips about the day via their social media accounts as if everybody is in race.

On the other hand, it looks like those days are an occasion to make their voices heard for related organizations and associations of disabled. As *Türkiye Körler Federasyonu* (Turkey Federation of the Blind) wrote on their website that;

²⁰ International Day of Disabled Persons, accepted by Turkey as a member of UN, was proclaimed in 1992 by UN General Assembly resolution 47/3. It aims to promote the rights and well-being of persons with disabilities in all spheres of society and development, and to increase awareness of the situation of persons with disabilities in every aspect of political, social, economic and cultural life.(UN 2020)

²¹The Year of the Disabled, declared in 1981 by UN General Assembly for a period of 10 years, has been celebrated as Disability Week every year between May 10-16 after 1981(İçli 2020).

In 1969, on the anniversary of the World Federation of the Blind's acceptance of this important day, which symbolizes the safety, independence and freedom of the visually disabled, as the White Cane Blind Security Day(Beyaz Baston Körler Güvenlik Günü), we, as visually disabled people all over the world, share our problems and solutions with the society we live with; we aim to invite our rulers to be sensitive.

In this context, we aim to announce the main problems and demands of the disabled to authorities by sharing them with the public once again(Türkiye Körler Federasyonu, 2021,my translation).

In sum, the society is familiar with especially the disability day of December 3 and the fact that, a certain week of the year is the week of the disabled. But, none of the participants made a completely positive comment to questions about the week and days of disability. On the contrary, almost all participants said that, those days were not mean anything to them. A couple of them pointed out that, they even did not remember when it happens and did not want to talk about the subject anymore. Those who were positive about certain days in a year for disability, stressed that what has been done in those days were inefficient and meaningless, as Neşe said;“At least we are remembered just for one week. I think positively about it, but, it is needed to do something more, just remembered for a week, I don't know, it comes and goes, nothing has been done.” Some of them said that they remember celebrations of those days only from their childhood, they have a day off at work right now, but nothing after primary school. Some added that many more people's participation can be ensured to those activities, only disabled people's families do. Some said, there should be useful activities, like Aydan;

It means nothing' to me. I heard from my mother yesterday that it was this week. Maybe we can think of it as a week to raise awareness. I think, it is not about a week for disable but, if something useful is desired to be done, for example, whether in a primary or secondary school, a teacher should give information about the visually impaired, especially the physically disabled, because people look at physically disabled people very differently, they wonder and stare... They need to teach the kids what kind of thing it is. For example, when seeing a physically disabled person, the child needs to know what to do, how to react, and this should be trained. Because there are not many disabled people around, that person rightfully stare, do not know what to do when saw a disabled person for the first time. They can say something like, can I help you. I think, they need to know what to do, in order to be a more conscious society.

Some said that, what is being done these days is a kind of celebration and it is wrong, like Mustafa;“Actually, we always have things to do, not just during the disabled week. Some associations and organizations do not understand this. Because, the disabled week is not something to celebrate. Some of them are doing things at those times only.” In addition some stated that, these special weeks and days for the disabled have been misconduct by some associations and people. Alp said;“It is the week that people are taking advantage of and making money on disabled people.” Some of the participants indicated that, anything performed and repeated discourses on these days were a kind of "showpiece", as Erkan;“Weekly awareness doesn't mean anything. Posts on social media, someone with a disability in news... seems ridiculous to me. They turn into public spot that are useless. It's like

a crash course, we've done a bunch of things, we'll show you all for a week.” And, Murat said about the subject that; “That day, people become aware, a little bit, and then the next day, life goes on like normal, they continue to live without give a damn. They only think to help and then pass by, they don't care.” When I asked related question during the interviews, I observed that some of the participants were uncomfortable and even slightly angry. The reason for this was not the question, but inaccuracies in activities of the disabled week and days. Melek;

It doesn't mean anything to me. I mean, first of all, the mindset has to change. Many strange studies are being performed, necessary or unnecessary. Yet people try to do something, okay, but, let's close our eyes, let's understand the blind... come on! Then let's close our ears or something, rubbish!. Something very different (to be a visually impaired), if you suddenly close your eyes and start walking, you will hit somewhere, and then you say that these people cannot walk like that either. After that, you think that the first blind person you meet on the street will hit somewhere. However, disabled people have the life experiences, gained practices. They do not live as the way you close your eyes. I recently read a news, a social worker conduct a study by closing people's eyes in a hospital. Then a participant who was the head of the women's branch of a political party, made a statement by crying melt into tears, saying something like, oh our poor disabled brothers and sisters... I don't understand why university students or social workers do this. If you are going to do something, you have to ask the opinion of those groups what to do.

Şule;

Normally, it is good for raising awareness, disabled people can speak and say, “we want an equal and disability-free life”, or people who are not disabled can participate, although a small number of similar things are done. In our country, we mostly make sentences at those ceremonies that start with “our disabled brothers and sisters” and end with “my God be pleased with you”.

As can be seen from the above-mentioned answers, these determined days to raise awareness about disability in the society do not work for the participants to a great extent. Because, to those visually impaired young people, carried out activities at these days are noneffective and discourses repeated are stereotypical. That means, those disability weeks or days do not matter for participants who were suffered from unconsciousness of disability in the society.

The wide-ranging announcements and activities of disability days or weeks, which have been repeated regularly every year for decades, would have been contributed to the continuity of the behavior of helping people with disabilities in the society. However, if the content in these activities is mostly addressed to people's sense of compassion, even the feeling of pity, it has problematic results. In other words, it is the supposed “deficiency” of the disabled people that is reminded and made visible in a sense, not, for instance, the benefits of using a white cane. This approach almost turns into a mechanism that reproduces the stigmatization of the disabled.

The invisibility of disabled people becomes both a cause and an effect here. In other words, people with disabilities are not seen as they actually are. The disability days or weeks are an example of the problem in the efforts to raise awareness of disability in the society in general. The activities are not carried out from the point of view of the disabled, therefore it inevitably would not be a functional

way for raising social awareness through potential of people with disabilities in those days. Instead, the disabled's presumed inadequacies are focused. Thus, in the activities aimed at raising social awareness about disability, for example, a visually impaired person can live her daily life without being dependent on anyone with appropriate training, cannot be visible for families. Or, a visually impaired who has independent movement, cannot give concrete information about the importance of yellow tactile pathways and so as the accessibility issues. It may not become visible that, disability is not just a "personal tragedy" of a bodily or intellectual disorder, hence why it is a socially constructed situation, cannot come to light. And consequently, in the words of the participants, it may not be understood that raising awareness in these days, does not mean "let's feel sadness for the disabled and hold celebrations to comfort them for a day".

The disability days mostly, again, are actualized with help-only approach for the assumed needy disabled. Most of what has been done in those days inevitably remains inefficient and insufficient, because their goals and how and which activities needed to be carried out are determined not from the window of people with disabilities, but by prejudiced understanding of disability. As conveyed in previous sections, it originates from misinformation and misconception, not from the information that actually exists. Therefore, in a sense, disability remains "unknown" in society. Moreover, it inevitably reproduces misconceptions and misinformation about people with disabilities. In other words, the help-only approach reconstructs the invisibility of the disabled once again.

In short, people with disabilities do not appear as they are, but as they are assumed in general. In these days, a social awareness about disability cannot be created which will not be forgotten the next day, therefore cannot have positive reflections on disabled peoples' lives. As a result of all this, activities that would improve the quality of life of disabled people cannot be put forward which motivates the disabled to be involved in social life.

5.3 Visibility of Disabled People

The invisibility of the disabled, which creates a basis for misinformation and misconceptions and ignorance towards the disabled in society, is one of the results of the help-only approach in the context of practices that reproduce each other like a vicious circle. In the cycle and dynamics of social life, it is also the source of the society's help-only approach to the disabled, and also the needy disabled assumption.

It is obvious that, all these concepts as help-only approach, needy disabled assumption and invisibility of disabled people contain extremely complex cause and effect relations with each other. For this reason, looking in reverse on the matter would help the picture to be seen more clearly in the light of the experiences of the participants. So far in the chapter, the invisibility of people with

disabilities and societal and cultural reasons for this have been analyzed. It is needed to point out some outcomes of “visibility” of disabled people to embodied the subject.

During my time at ODED, I personally witnessed how young people who actively use white canes, act independently and manage their daily lives on their own inspire their visually impaired peers who do not do these as the result of above described reasons. In this context, the story of Esra, one of my students at ODED and also interviewee, would be a concrete example to reveal the effects of “visibility” in disabled people’s daily life. In addition, universities where disabled people are more visible compared to other social spaces will be examined to see the subject from a broader framework.

Esra was a totally blind high school student at the age of 20 and had a kidney transplant from her mother. She, as she said, could not speak as much as she wanted during the lessons because she did not want to say anything stupid. She was also refusing to use white cane. Esra liked to be at home, being in her room alone, and watching TV series and listening music more than anything else. She was saying that she wanted to numb her brain, always prefer to dream because there was no sadness there.

At the beginning of the semester, Esra could not used to get her own coffee because she was afraid of burning her hand, or go out by her own because she thought that she could not. Her mother was always at ODED to prepare her hot beverages or anything needed. Besides, her mother was bringing Esra to and from wherever she wanted. Because neither of them were convinced that Esra could go out alone, walk the streets or go to places she knew.

On the other hand, Esra was a very smart young lady, very sensitive, literally loving and very fond of communicating with people. She was the visually impaired person who were using smart phone and computer most skillfully I have ever seen, that visually disabled people I have met use smartphones much more practically than sighted people to my observations. Esra was contacting famous people she had a fan on and meeting them outside. She had virtual friends in addition to real ones with whom she could chat about the series she watched constantly thank to internet and technology.

In fact, I have recognized the importance of assistive technology for disabled people by the help of her at first, and also other students. That is, even if Esra could not take hot beverages by herself from the kitchen, she could order lunch by virtual cuisine platforms with her smartphone for her mother, friends and herself. Visually disabled friendly interfaces, modes of interactions, cell phone applications and computer programs are largely eliminating problems caused by visual disorder in daily life. Text-to-speech applications, audio books, audio description applications, audio steps applications, navigational assistance modules, and more can be given as examples of those assistive technology items. Participants mentioned all those technology based products in the frame of education, working and socialization processes within the scope of spending quality time.

When we back to the story of Esra, she and her mother necessarily used metro or bus and then passed the Kızılay square five days of every week for coming to ODED. As it is mentioned before,

Kızılay is a crowded neighborhood which the transportation hub is there. Thus, sightless persons with their white canes can be seen more than most of the streets in Ankara. At ODED, Esra met with some sightless peers who always use white cane, that one of them was calling his white cane as “my best friend”. After a while, Esra and her mother observed that, some of blind students were able to come and go to ODED on their own. As the consequence, both of them were convinced that Esra could go out on her own as a result of the familiarity formed by seeing that other people with similar disabilities could do this in ODED as well as on the streets.

Some weeks after the beginning of the semester, Esra began to walk to a shop across the street with a friend. One day Esra and I went together to a supermarket on the side street. We walked side by side but she did not want to take my arm, because she had memorized the road. Moreover, she said that she was going there alone, experiencing that people helped her if she lost direction. She added that, only once a person did not helped her even though she asked, but that it was not a problem as she found her direction very soon by her own.

After some more weeks later, Esra began to carry a white cane however she was not always prefer to use it. She had recognized that she was able to prepare hot beverage by herself like some of others at ODED. About some months later, she asked her mother not to stay with her in ODED and take time for herself that there was no need to wait her anymore. As time passed, Esra started using a white cane constantly, even when she was with her mother. At the end of the semester, she offered me to drink a cup of coffee, and prepared it for both of us by herself.

The following semester, Esra started her university education by passing the entrance exam. And, about a year after our last meeting, she called me and said that she always commuted to and from the university campus on her own. Also, although she still likes to spend time alone in her room, she did not have time to be at home mostly because she was out with her friends on the university campus.

As mentioned in the previous sections, Esra used to consider the white cane as a burden to herself, something that would cause her to be stigmatized as a needy disabled in the society. But, after she had time with people who use canes in their daily lives, that is, as she became familiar with the usage of white cane, she began to see it as a device that makes the life easier, just like the smart phone used by everyone. When both her mother and Esra saw that the visually impaired could walk down the street on their own or prepare their own hot drinks, it became commonplace for them that the disabled could, not that they could not. The visibility of all this created a familiarity in them, just as in other visually disabled young people I had observed in similar situations. As a result, Esra, who wanted to live in her room by daydreaming and watching soap operas before, began to spend time with her friends on the university campus, where access problems were lower than other spaces. Besides, since being seen with her white cane was no longer a problem for her, she preferred to be involved in social life with the independence provided by the cane.

People with disabilities like Esra are more visible at universities compare to other social spaces. That is, significant number of university campuses are more disabled-friendly, in other saying barrier-free places. Available blind guide paths or pedestrian ways between buildings, wheelchair ramps, elevators, accessible toilets and so on have been added to their construction design to ensure this. Besides, some universities have student clubs and communities related to disability. In addition, it became compulsory for all universities to have a unit for disable students in accordance with *Yükseköğretim Kurumları Engelli Danışma ve Koordinasyon Yönetmeliği* (Regulation on Higher Education Institutions Disabled Counseling and Coordination, Official Gazette No: 27672 of 14.08.2010) which was approved in 2006 and revised in 2010(Disability Support Office, 2020).

To Şule, who was a student representative, this regulation was an achievement from *Engelsiz Üniversite Çalıştayları* (Unimpeded, barrier-free, University Workshops) held every year by YÖK. As a result of this regulation, Şule explained that as;

You are now asked if you have any disability during your first enrollment to the university. In this way what we need is known and the disabled students can be reached more easily. It was very surprised for me to recognize that people really do if demanded. I mean, for instance, I was taking my own computer to exams, the instructor said, how do I know that you are not cheating? I said you are right, then I need a computer with a screen reader program here. The next semester, a screen reader program was purchased to the department for me. They bring the computer, I do my exams there, then I give it back. It has been like this for about two years. Or, for example, about a friend of mine with an orthopedic disability, because the elevator was broken in the building, her mother was bringing and taking her, so we got the elevator repaired.

Since 2007, those workshops with the motto of *engelsiz üniversite* (unimpeded university) have been managed by YÖK and mostly carried out by a different university each year²². During those workshops²³, main subjects were participation of disabled people in university life under equal conditions, education and accessibility issues and employment. Besides, panels have been organized with some other subjects like, raising public awareness on equality of rights and discrimination, the issue of invisible disabilities, communication of disabled persons, employment of people with disabilities, accessible architecture and so on(YÖK, 2021b).

The participants, especially those who were university students, evaluated university circle separately from the society in general when they were talking about issues of people's unawareness about disabled persons during the interviews. For instance Semiha said that;“Thank to them,

²² “The first Barrier-Free(unimpeded) Universities Workshop was held on May 19, 2007 at METU. With the positive feedback of the participants and the satisfaction of the information sharing, the workshops have gained continuity and the Barrier-Free Universities Platform has been established in October 2007, currently has 420 members representing 120 universities(September 2012). The academic and administrative staff of the university and the Disabled Student Representatives who are interested in the issue of disability can become a member of the EngUni Platform”(Uludağ University 2019, my translation).

²³ 2007 and 2008 Middle East Technical University, 2009 Istanbul University, 2010 Ege University, 2011 Ankara University, 2012 and 2019 Yeditepe University, 2013 Süleyman Demirel University, 2014 Atatürk University, 2015 Muğla University, 2016 Anadolu University, 2017 Bülent Ecevit University, 2018 Hacettepe(YÖK 2021b)

universities do not cause trouble like that” when we were talking issues of obtaining accessible education materials. The participants also added that their progressed communication abilities with sighted persons as the result of their ages and experiences effects this circumstance. But still, they specifically stated that people’s behaviors to them in and around universities were more conscious than the society at large. They also emphasized the awareness of people around universities were higher than others. For instance Meltem said that;

I never cross the street alone. When crossing the street close to the university campus, I usually get scared. I don't know if people understand that I'm scared, but they sincerely ask, "Shall I help you?", then I thank you, then we cross the street, then they move on, then I am happy. There are not much of them in Kızılay, it is not like that around here in the city center. There are many students and disabled students at the university, and the students are very understanding. I was very comfortable in METU, for instance. Although there were very few disabled people there, but even if people did not know, they were conscious.

Although there are few number of disabled students as Meltem said, the METU without Barriers Student Club and the Disability Support Office are very active. Actually, in order to access these units that are active in almost all universities, it is enough to write "edu.tr" domain name extension, or the name of the university, and the word *engelsiz* (barrier-free) in the internet search engine²⁴. In addition, it is observed that the number of structuring in universities for the access of disabled students to information is increasing day by day. In this regard, studies are carried out to make use of the information resources of libraries as well as physical access, especially in university libraries²⁵.

Besides barrier-free student units and libraries, there are also notable achievements on accessibility subject in different university units. For instance, most of the participants mentioned that they were benefited audio books by GETEM(Boğaziçi University Technology and Education Laboratory for the Visually Impaired)(GETEM, 2020). There is an integrated college for hearing disabled people in Anadolu University(Anadolu University, 2021b). The adequacy of these applications is the subject of a different research. But, what is important here is that, people with disabilities are seen and work is carried out on this issue. Another aspect is that, universities are an environment where students with disabilities can express themselves as well as their problems and can make improvements on these issues.

Based on the participants' told, it is understood that, universities recognize people with disabilities in general, because there is a perspective that takes into account the accessibility needs of disabled in physical, social and academic contexts. Still, participants who were university students mentioned problematic situations at universities. However, they also emphasized that they feel more comfortable at those locations. For sure, it is not possible to state that all university spaces are

²⁴ <https://engelsiz.bartın.edu.tr/>, <https://engelsiz.trakya.edu.tr/>, <https://engelsiz.erciyes.edu.tr/> <http://engelsiz.deu.edu.tr/> <https://ebk.usak.edu.tr/>, <https://www.bilgi.edu.tr/en/life-at-bilgi/student/student-support-center/unit-for-students-with-disability/> <https://studentguide.ku.edu.tr/en/new-students/orientation-days/7-questions-7-answers/disabled-student-unit/>

²⁵<https://engelsizbilgimerkezi.istanbul.edu.tr/>,<https://lib.metu.edu.tr/users-disabilities><https://kutuphane.kapadokya.edu.tr/kutuphane-hakkin-da/engelsiz-kutuphane/> <https://kutuphane.marmara.edu.tr/hizmetler/erisilebilirlik>

disabled-friendly. But, it is possible to say that disability is more visible at universities. In fact, people with disabilities are more visible at those spaces. And as the participants expressed, they feel reflections of this visibility in their life that increases their quality of living.

In a result, the experiences of the visually impaired participants allow me to argue that the disabled are physically and metaphorically invisible in social life. Although activities on disability are theoretically considered to be at a relatively satisfactory level, in practice their contribution to the quality of life of the disabled is reflected incompletely and inefficiently. One of the main reasons for this is the invisibility of the disabled which framed by the assumption of needy disabled and constantly reproduced with help-only approach.

There is a lack of knowledge and awareness about disabled people in the society that are framed by misconception and misinformation. So much so that, even the social construction phase of disability is also invisible in the society. Thus, for example, efforts to raise awareness about disability are based on impressions arising from assumptions about impairments. Whereas, universities for instance, as places where disability is relatively more visible, reveals that visibility has direct effects on disabled persons life quality.

CHAPTER 6

CONCLUSIONS AND SUGGESTIONS

The research had two goals. The first aim of the study was investigating the fundamental social and cultural perspectives, understandings and approaches of the society that were claimed to cause inefficient practices in disability-related issues in the context of invisibility based on daily life experiences. The other aim of the study was to transfer the experiences of disabled people to both academia and the society. For these purposes, the research was carried out by participating about eight months in daily lives of visually impaired young people who were preparing for the university entrance exam at ODED, a non-profit educational support organization, and by conducting in-depth interviews with 15 visually impaired people between the ages of 18-23 living in Ankara.

According to the findings obtained as a result of the study, the initial assumptions and arguments were confirmed based on participants' experiences. That is, the practices on disability issues are largely inefficient, ineffective and inconsistent. People with disabilities are, physically and metaphorically, invisible in social life. There is a direct correlation between this invisibility and unproductive outcomes related to disability issues. And, the social and cultural perception, understanding and perspective that people from every segment of the society put into practice regarding disability are one of the main reasons for this inefficiency and ineffectiveness.

The fundamental social and cultural reasons for the inefficiency and ineffectiveness of individual and institutional practices on disability issues are, the help-only approach, needy disabled assumption and invisibility of disabled people.

From the experience and observations acquired in the process of participation in daily lives of visually impaired young people, as well as in-depth interviews, it was concluded that, there is an understanding and perspective towards disability arising from the social and cultural characteristics of the society. This perspective stems from the assumption that disabled people “cannot do anyway” and is based solely on helping. Helping the disabled is highly internalized and widespread by different segments of the society, as if it is a natural right of the disabled. Although this understanding provides convenience from time to time in the everyday lives of people with disabilities, it also does not leave room permanent improvements and therefore creates an obstacle for people with disabilities. Because this approach, based on the acceptance that there is nothing that can be done but help directs almost every activity on disability.

As a result of the research, it has been revealed that, this approach of people who compose the society are shaped by a deep-rooted social and cultural perspectives and was necessary to express the approach with a concept that included these basic features. But, the concepts that I had the opportunity to examine in the existing disability studies literature were not enough to meet this need. Therefore, the conceptualization proposed to distinguish this approach, which has problematic consequences for the disabled, from the act of helping, which facilitates daily life of the disabled to some extent, is the “help-only approach”(sadece-yardım yaklaşımı). The help-only approach refers to the social understanding which creates all kinds of activities that just provides impermanent and inadequate conveniences to persons with disabilities. Since it is based on the perspective that functionality would not possible, it does not contribute to the functionality of the person being helped. Because, whatever is done, it includes a prejudice that accepts persons with disabilities as incompetent because of the mental or physical disability. So, according to help-only approach, the only thing that can be done about the disabled is to help them.

Based on the experiences of the participants, it has been determined that the help-only approach is established in all segments of the society, including the disabled, their families, people in education and working life, people they encounter in social life and even those who operate the state apparatus. Since the approach does not leave room for the option that disabled people can be self-sufficient individuals in the first place, it causes inefficient results of what is done regarding disability. And consequently, for instance, the option of providing self-sufficiency with different training techniques cannot be noticed, the logic of regulating environmental accessibility cannot be comprehensible and rights-based laws cannot be effectively enforced.

One of the issues that most disturbed the participants was that, they were perceived as needy in the society. Here, neediness refers to the state of not being self-sufficient. As a result of the help-only approach, the needy disabled assumption is constantly reinforced within people with disabilities as well as in the society. In order to explain this situation concretely, the use of and the perception of the white cane can be given as examples. According to the experience of the participants, it is very important that the visually impaired receive independent movement and everyday life skills training at an early age so that they can become self-sufficient individuals. And, the white cane is the first and apparently simplest and practical way to achieve independent movement. However, visually impaired people mostly do not use white canes. According to the participants, the reasons for this were; not to be labeled as needy, not to be aware of the conveniences it provides, and not to receive training in using a white cane on time. Besides, families cannot accept the necessity of acting independently, or unaware that independent living is possible, as well as the contribution of using a white cane to self-sufficiency. When environmental barriers and social ignorance are added to these, the white cane, which is expected to facilitate the life of the visually impaired and contribute to their independent living, is seen as the reason for being perceived as needy disabled. Thus, the perception that the visually impaired cannot be self-sufficient continues within people with disabilities and in the society.

The accepting of being disabled means being needy, reduces the life quality of people with disabilities. Because, since it is assumed that visually disabled people need inevitably others to be able to achieve any kinds of their requirements, all relevant activities (and inactivities) are carried out based on this and as the consequence ineffective results are obtained.

The examples like the usage of white canes, which were revealed based on experiences of visually disabled participants can be increased, but the point is, the source of this inefficiency comes from the assumption that disability is identified with neediness due to its supposed nature of impairment and what can be done in this regard is limited in any case. Thus, the perception of needy disabled leads to non permanent help-only practices that can only and (maybe) provide momentarily relief. And, just like a vicious circle as the result of social life dynamics, help-only approach and its practices naturally constitute and foster needy disabled assumption.

When this vicious circle was examined deeper, the issue of invisibility of disability, which in fact was immediately noticed at the beginning of the research, again manifested itself. But, it is not the invisibility of “disability” that is at the stake here, but the invisibility of “disabled people”. Because as the study progressed, it was realized that the sensitivity of the society to the disability situation obscured the issues related to the relevant practices. Therefore, in order to clarify invisibility, the impairment and disabled people had to be considered separately.

Invisibility of disabled people refers here both its embodied meaning and its metaphorical meaning. That is, disabled people are not being physically involved in public life at the rate of their existence, therefore they are invisible. At the same time, they are not recognized in the society, because they are seen not as they really are, but through stereotypes and prejudices regarding disability, and they are not noticed with their own truths.

Negative stereotypes and prejudices that lead to discrimination in public life are fundamental concepts that actually transform a physical or mental disorder into a disability which are commonly experienced around the world. Cultural differences reveal how negative stereotypes, prejudices and discrimination in society are experienced and even reproduced in daily life. The experiences conveyed in this research demonstrate that, disability is not known in society and this is accompanied by misinformation and misconception about disabled people. This is one of the main reasons for the help-only approach, which fosters the needy disabled assumption in society, that consists of multi-layered social causes and effects of prejudices against people with disabilities.

Being different is the key to social attitudes towards people with disabilities. According to the participants, which my inference as a result of my observations is also in this direction, when people encounter things that they do not see and do not know, that is, unfamiliar with, their reactions take place within the framework of stereotypes and prejudices. Therefore, the behaviors towards the disabled are mostly rooted in the cultural stereotypes of the society, which lead to prejudices and even discrimination.

For sure, the prejudice and especially the discrimination faced by the disabled cannot be reduced to a single reason. However, one of the important results of this research is that, it should not be ignored that the lack of information in the society, together with misconceptions and misinformation, is a very important reason for the social attitude towards the disabled. Because the participants, including the preliminary studies of this main research, persistently repeated in different contexts that people did not know what disability was. In addition, the clearest proof of the fact that the disabled are not known in the society and the consequences of this as well is the lack of knowledge of the visually impaired participants about people with other disability categories. That is, the interviewees, as members of the society, were mostly unaware of what other types of disability are, the effects of these disorders on people with disabilities, the barriers they encounter in all areas of social life and how they actually live their lives. Instead, they had subjective beliefs and feelings about presumed incapable people and what needs to be done for them. There were even some participants who said some discourses and hearsay information that they thought wrong to be told about themselves for those with other disabilities. Therefore, what should be emphasized here is not only the lack of information, but also misinformation and misconceptions about the disabled, which reinforces the disadvantaged position of the disabled in society.

The invisibility, as a basis for the lack of information, misinformation and misconceptions about the disabled in the society, can lead to the continuation of the help-only approach, hence the assumption of the needy disabled, in the context of daily life. This assumption and approach is also one of the reasons of constructing the invisibility of disabled, resulting in the reproduction of the disadvantaged position of the disabled in social life. Lack of knowledge, misconception and misinformation about people with disabilities are among the decisive causes of the social attitude towards the disabled that should not be ignored. For this reason, awareness raising activities on disability, for example, are not carried out on the potential of the disabled. Instead, people's feelings of compassion and even pity are often targeted which fueling stereotypes and prejudices against disabled people.

The help-only approach, the needy disabled assumption and the invisibility of the disabled contain extremely complex cause and effect relations with each other. Therefore, looking in reverse on the issue would help to see the picture more clearly and at the same time to confirm the conclusions of the research. For this reason, it is needed to point out some outcomes of “visibility of disabled people” to embody the subject both in individual level and spatial level.

During my long time with visually impaired young people, I have observed that to be familiar with disabled people who “can do” has the effect of encouraging them and related with that increasing their quality of life. One of the most concrete examples of gaining this familiarity was the ability of visually impaired people to go from place to place on their own, to move independently, or to know and communicate with self-sufficient people who meet their personal needs. This familiarity either created or reinforced the perception that “disabled people can do”. Thus, for example, using a white

cane turned from a “burden” to a means of independent living for them. In other words, the visibility of visually impaired people who lead their daily lives on their own in social life has had an effect that increased the quality of life for the visually impaired young people I knew personally. Because the state of self-sufficiency meant that the “cannot” perception that was settled in the society turned into “can do”, and had a life-changing effect.

The situation described above was the result of situations where the disabled were physically visible. An example of spaces where the disabled are figuratively visible are universities. Participants constantly expressed in different contexts that they were very comfortable on university campuses, where disabled people are more visible than other social areas. Because most university campuses are more disabled-friendly, that is, barrier-free places. Namely, these university campuses include blind guide-ways or pedestrian paths, wheelchair ramps, elevators, accessible toilets, as well as accessible education services. In addition, some universities also have student clubs and communities for the disabled. Besides, there should be a disability unit in all universities at the administrative level. The adequacy of these practices are not the subject of this study. However, the important thing here is that disabled people are more visible than other social areas because they are noticed and recognized in universities. Another very decisive aspect is that universities are an environment where students with disabilities can express themselves and their problems and make improvements in these subjects in the physical, social and academic context.

From this point of view, I should emphasize that ensuring the presence of disabled people in social life and making them familiar with both other similar disabled people and the general society will prevent prejudices about disabled people to some extent. Because, for instance, all of the participants with independent movement talked about the support of their friends in making the use of white canes practical, even at a late age. It was not just a way to learn technical requirements. It was also proof to them and their families that visually impaired people could be self-sufficient. For this, as the first step, for example, visually impaired people and their families need to be familiar with visually impaired individuals who are self-sufficient. Therefore, developing familiarity with the disabled people in society will convince people with disabilities and their families that they “can do”, and to some extent prevents people from developing stereotypes and prejudices based on assumptions.

It is obvious that, social education or awareness raising activities contribute to the improvement of the quality of life of the disabled. And, rights-based arrangements are essential. However, mainly, if familiarity is created in social life, information about disability and people with disabilities can be spread to society, misinformation and misconceptions can be avoided to some extent. Therefore, I argue that this familiarity, that is, the visibility of the disabled, is one of the essential factors for the right-based gains to be put into practice efficiently in social life.

Disabled people should be seen and listened in the social life. The days and weeks of persons with disabilities will be both an opportunity and an example for the society in this context. Disabled people should define the framework of activities on these days. I believe that no one knows more

accurately than people who live together with disabled and non-disabled people on how to raise awareness of the disabled in society. Only then, the events held on these days actually can be an opportunity to raise awareness.

Another way to awareness raising as well as familiarize the society with disability and the lives of people with disabilities is to transfer the experiences of people with disabilities to the society and the academia, which was one of the main purposes of this research. Transferring the experiences of the disabled to the society will be an element that enriches the culture of the society. But, the main contribution will be to be informed the society about disability lived and understand people with disabilities. This will be an important step towards breaking the needy disabled assumption and help-only approach, and will be a significant way to ensure the visibility of the disabled people. That will lead to correctly identify the problems exposed to disabled people, and then, leads to create correct solutions to these problems.

In this way, it would be possible to ensure that the aim of activities related to disability is to develop permanent solutions instead of providing temporary relief. Maybe, by this way, the sensitivity of disability and the tendency to help the disabled, that entrenched in the society, can evolve into an understanding of the support. And, perhaps, in this way, the society would approach to the disabled not with help-only approach but with the support-approach, that offers permanent solutions in line with the wishes and requirements of the disabled.

There have been solid evidences through the visually disabled participants' experiences in this study that conveyed and analyzed throughout the thesis. Those allow me to argue that help-only approach, which guides almost all activities related to the disabled, constitutes an obstacle to permanent solutions for the disabled and therefore construct needy and invisible disabled. People with disabilities are, physically and metaphorically, invisible in social life. There is a lack of knowledge and awareness about disabled people in the society that are framed by misconceptions and misinformation about them.

The invisibility of disabled is one of the underlying hinders to any activities for improving disabled people's living conditions, by inevitably causing inefficient and inadequate implementations. In other words, the needy and invisible disabled people are constituted through the help-only approach in disability related activities. But at the same time, a vicious circle is formed due to people's influences and interactions that constantly construct and reproduce each other in social life. Accordingly, the inefficiency and inconsistency of activities aimed at improving the quality of life of the disabled is the invisibility of the disabled as one of the sources of the needy disabled assumption that leads to the help-only approach.

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APPENDICES

A. INTERVIEW QUESTIONS

Kişisel bilgiler

- 1 Yaş, cinsiyet, görme oranı, medeni durum, eğitim durumu, mesleği
- 2 Nerelisiniz, nerede büyüdünüz?

Gündelik yaşam

- 3 Bir gününüzü anlatır mısınız
- 4 Evde mi dışarıda mı vakit geçirmeyi seversiniz? Neden?
 - 4.1 Dışarıda nerelere gidersiniz? Neden?
 - 4.2 Toplu taşıma kullanıyor musunuz? Bu yerlere nasıl gidiyorsunuz?
 - 4.3 Alışveriş yapar mısınız, AVM ye yada pazara gitmeyi sever misiniz? Hep gittiğiniz belli yerler var mı, neden? / (Hayır ise), neden?
 - 4.4 (Gündelik yaşamınızda sürekli destek aldığınız belli kimseler var mı, nasıl?)
 - 4.5 Dışarıda, sokakta, otobüste, metroda vb. insanların size davranışları nasıldır?
 - 4.6 Sizi rahatsız eden belli tepki, söylem yada davranışlarla karşılaşılıyor musunuz? Evet ise, bunların sebebi sizce nedir?
 - 4.7 Sizi memnun eden belli söylem yada davranışlarla karşılaşılıyor musunuz? Evet ise, bunlar sizi neden memnun ediyor, bu tür davranışların sebebi sizce nedir?
- 5 Cep telefonu, bilgisayar kullanıyor musunuz? Bu (yeni) teknolojiler sizin gündelik yaşamınızı etkiledi mi/etkiliyor mu? Nasıl ?
 - 5.1 Sosyal medya kullanıyor musunuz, nasıl? Sosyal medyada gerçek hayatta tanımadığınız bir çevreniz yada arkadaşlarınız var mı? (Onların herhangi bir engeli var mı, sizin görme engelli olduğunuzu biliyorlar mı?)
- 6 Görme engellilikle veya engellilikle ilgili televizyonda, radyoda veya internette sürekli karşılaştığınız ve rahatsız olduğunuz şeyler oluyor mu? Bunlar sizi neden rahatsız ediyor? Sizce neden bu tip şeyler yayınlanıyor?
- 7 Gündelik yaşamınızda en yoğun şekilde hissettiğiniz ihtiyaçlarınız nelerdir?
 - 7.1 Bu ihtiyaçlarınız karşılanıyor mu? Nasıl?
 - 7.2 Karşılanmayan ihtiyaçlarınız nelerdir?
- 8 Gelecekten umutlu musunuz? Evet veya hayır ise neden?

Eğitim

- 9 Yazma biliyor musunuz(görenyazı), nasıl öğrendiniz? İşinize yarıyor mu? - Braille alfabesi biliyor musunuz, nasıl öğrendiniz? İşinize yarıyor mu, nerede kullanıyorsunuz?
- 10 Hangi okullara gittiniz, sevdiğiniz okullar sevmediğiniz okullar var mıydı? Neden ?
 - 10.1 (Kaynaştırma eğitim yapan bir okula gittiyse) Görme engelli çocuklara kaynaştırma eğitim yapan bir okula gitmelerini tavsiye eder misiniz? Neden?
 - 10.2 (Görme engelli okuluna ve/veya özel eğitime gittiyse) Orada görme engellilerin günlük yaşamlarını kolaylaştıracak yaşam becerileri eğitimi aldınız mı?
- 11 (Hatırladıkça) şu olsaydı daha iyi eğitim alabilirdim dediğiniz bir durum oldu mu?
- 12 (Hatırladıkça) şu olmasaydı bu eğitimi alamazdım dediğiniz bir durum var mı?
- 13 Sizce görme engellilerin okulla ilgili yaşadıkları özel sorunlar (öğretmenlerle, arkadaşlarla veya eğitim sistemiyle ilgili) var mı? Sizin bu konuda tecrübeleriniz oldu mu?
 - 13.1 (Varsa) Bu sorunlar neden kaynaklanıyor-neden çözülüyor sizce?
 - 13.2 Hala aynı sorunlar devam ediyor mu biliyor musunuz?
 - 13.3 (Üniversite eğitimi aldıysa) Bu sorunlar üniversitede de var mı?
- 14 Başka engeli olanların(işitme, ortopedik, zihinsel...) bu tip sorunlarının olup olmadığı hakkında bilginiz var mı?

Aile ve akrabalar

- 15 Evde kiminle/kimlerle birlikte yaşıyorsunuz?
 - 15.1 İşleri, yaşları, eğitim durumları nedir?
 - 15.2 Evde birlikte yaşadığınız aile büyükleri var mı?
 - 15.3 Evde veya akrabalarınız içinde başka görme engelli/engelli var mı?
 - 15.4 Ev işlerine yardım eder misiniz?
- 16 Nerede yaşıyorsunuz (semt, kiracı-evsahibi, kendinize ait odanız var mı) ?
 - 16.1 (Ailenin gelir kaynağı nedir?) Türkiye şartlarında gelir durumunuz için ne dersiniz?
Ortalama, ortalamanın altı veya üstü?
 - 16.2 (Asgari ücret aylık TL, buna göre gelirin ne düzeyde?)
- 17 Sizce aileleri engelli aile fertleri hakkında ne düşünüyorlardır?
 - 17.1 Görme engellilerin aileleri veya akrabalarıyla yaşadıkları özel sorunlar var mı?
(Varsa) Bu sorunlar sizce neden kaynaklanıyor?
 - 17.2 Sizin bu konuda tecrübeniz oldu mu?
 - 17.3 Başka engeli olanların bu tip sorunlarının olup olmadığı hakkında bilginiz var mı?
 - 17.4 Çevrenizde ailesinden destek görmeyen engelli kişiler var mı? (Evet ise) nedenini biliyor musunuz?

Çalışma Hayatı

- 18 Çalışıyor musunuz? Ne iş yapıyorsunuz? İşinizden memnun musunuz? Neden?
- 19 (Çalışmıyorsa) Daha önce hiç çalıştınız mı? İş arıyor musunuz, arayacak mısınız? / Neden?
- 20 Görme engellilerin (işyerleriyle ve çalışma arkadaşlarıyla yaşadıkları) özel sorunlar var mı? Varsa bu sorunlar neden kaynaklanıyor sizce? Sizin bu tip tecrübeleriniz oldu mu?
- 21 Başka engeli olanların (işitme, ortopedik, zihinsel...) bu tip sorunlarının olup olmadığı hakkında bilginiz var mı?

Sosyal Yaşam

- 22 Arkadaşlarınız var mı, onlarla neler yaparsınız, arkadaş seçiminizi neye göre yaparsınız? (Görme engelli olmayan arkadaşınız var mı? Hayır ise, neden?)
- 23 Yeni insanlarla tanışmayı sever misiniz? Evet / hayır ise neden?
- 24 Düşünlere gider misiniz? Düşünleri sever misiniz? Orada insanların size davranışları nasıl olur? Sizin insanlarla iletişiminiz nasıldır?
- 25 Sinema, tiyatro veya konsere gider misiniz?
- 26 Tatile çıkar mısınız? Nerelelere? Tatile çıkarken özel dikkat ettiğiniz şeyler var mı?
- 27 Boş zamanlarınızda neler yaparsınız? Hobiniz var mı? Nasıl öğrendiniz?
- 28 Yapmak isteyip de insanların olası tepkileri nedeniyle yapmadığınız, yada çekindiğiniz şeyler var mı? / (Varsa) Bu olası tepkiler nelerdir?
 - 28.1 İnsanların size engelli olduğunuz için başka insanlardan farklı davrandıklarını hissettiğiniz oldu mu? Evet ise, bu farklılığı nasıl tanımlarsınız? Bu davranışın kaynağında size göre ne var?
- 29 (Görme engelli olduğunuzdan) size kolaylık sağlanacağını düşünerek yapmaya başladığınız şeyler oldu mu?
- 30 Engelliler günü veya haftası size ne ifade ediyor? Bu haftada her zamankinden farklı şeyler yapıyor mu?

Engellilik algısı, tanımı

- 31 Kendinizi anlatmanızı isteseler nasıl anlatır, tanımlarsınız?
 - 31.1 Aileniz, akrabalarınız / komşularınız arkadaşlarınız da sizi bu şekilde mi anlatırlar?
- 32 Bilmeyen birine görme engelli olmayı nasıl anlatırsınız?
 - 32.1 Görme engelli olduğunuzu ilk ne zaman farkettiliniz, nasıl?
- 33 Kör, âmâ, görme engelli veya görme özürlü terimlerinden hangisini kullanmak doğru? Neden?
 - 33.1 Bu kelime size ne ifade ediyor?
- 34 (Görüşmeci normal kelimesini kullanırsa) Sizce “normal” nedir?

Devlet

- 35 Sizce devlet görme engellilere destek olmalı mı? Neden? (Evetse) Nasıl destek olmalı?
- 36 Sizce devletin görme engelliler için yapması gereken ama yapmadığı-yetersiz yaptığı şeyler var mı?
 - 36.1 (Varsa), sizce neden bu dediğiniz şeyler yapılmıyor?
 - 36.2 Devletin başka engelleri olanlar için yapması gereken ama yapmadığı şeyler olup olmadığı hakkında bilginiz var mı?
- 37 Siz ve /veya aileniz devletten engelli maaşı ve/veya araç gereç desteği alıyor musunuz? (Evet se) Süreç nasıl işliyor, o konuda sorun yaşıyor musunuz? (Evetse) Bu sorunlar sizce neden oluyor?
- 38 İnsanlar size aldığınız bu devlet destekleri ile ilgili soru soruyorlar mı, nasıl tepkiler veriyorlar? Sizce bu tepkilerin nedeni ne?
- 39 Görme engelliler için kaldırımlara yapılan sarı yolu kullanıyor musunuz?
- 40 Hiç yerel veya genel seçimlerde oy kullandınız mı?

Sivil Toplum Kuruluşları

- 41 Siz ve / veya aileniz sivil toplum kuruluşlarından herhangi bir destek alıyor musunuz? (Evetse) Süreç nasıl işliyor, o konuda sorun yaşıyor musunuz? Eksiklikler var mı? (Varsa) Bu eksiklikler sizce neden oluyor?
- 42 Siz herhangi bir sivil toplum kuruluşunda gönüllü olarak çalışıyor musunuz? (Hayırsa) Çalışmak ister miydiniz, neden?

Toplum

- 43 Görme engellilerin çarşıda, yolda, sokakta yaşadıkları özel sorunlar var mı?
 - 43.1 Varsa, bu sorunlar çözülebilir mi? (Hayırsa) neden? (Evetse) sizce nasıl çözülebilir? Sizce o zaman neden çözülüyor?
 - 43.2 Başka engeli olanların (işitme, ortopedik, zihinsel...) bu tip sorunlarının olup olmadığı hakkında bilginiz var mı?
- 44 "Toplumumuzda 'engelli' dendiğinde ne anlıyoruz bir kelime, kavram veya benzetme ile cevaplayınız", dense ne cevap verirsiniz? / Neden?
 - 44.1 Sizce insanlar yolda, sokakta ve benzeri yerlerde görme engellilere nasıl davranıyorlar?
 - 44.2 (Verilen cevaba göre gerekirse) Sizce nasıl davranmalılar? Örnek verir misiniz?
 - 44.3 Engellilere olan davranışlarımızla engelli olmayan bireylere olan davranışlarımız arasında fark var mı? (Evetse) nedir bu farklar?
 - 44.4 Sizce, toplumumuz görme engelli olmayı nasıl algılıyor? Bu sizce yerinde bir algı mı? Neden? Sizce bu algının kaynağı nedir?

- 45 Elinizde sihirli bir değnek olsa insanların görme engelliler hakkındaki hangi düşüncelerini değiştirmek isterdiniz? Neden?
- 45.1 Sizce insanlar neden bu şekilde düşünüyorlar?
- 45.2 Sizce bu düşüncenin değişmesi için yapılabilecek birşeyler var mı?
- 45.3 İnsanların bu bahsettiğiniz düşünceleri öbür engelliler (işitme, ortopedik, zihinsel...) için de geçerli mi?
- 46 “Bu bizim geleneklerimizde var onun için engellilere şöyle davranıyoruz/davranmalıyız” dediğiniz bir durum var mı?
- 47 Sizce toplumumuzda (görme) engellilerin yaşamları biliniyor mu? Evet ise, nasıl biliniyor, bu kanıya nasıl vardınız? Hayır ise bunun nedenleri ne olabilir?
- 48 “Engelliler bence şu konularda yanlış yada hatalı davranıyorlar”, dediğiniz konular var mı?
- 49 Başka engeli (işitsel, ortopedik, zihinsel...) olan kişilerin yaşamları hakkında bilginiz var mı?
- 49.1 Sokakta, okulda vb. hiç tanımadığımız böyle birisiyle karşılaştınız ona nasıl davranmanız gerektiğini bilir misiniz? (Bilmiyorsa), sizce neden bilmiyorsunuz?
- 50 2002 istatistiklerine göre ülkemiz nüfusunun yüzde 10 u, yani her 10 kişiden biri engelli, bunu biliyor muydunuz?
- 50.1 Engellilerin bu oranda toplumumuzda fiziken görünmediğini ve temsil edilmediklerini düşünüyorum. Siz bu konuda ne dersiniz? (Katılıyorsa), bu görünmezliğin sebepleri sizce nedir?
- 50.2 Sizce toplumda görünmez olmak ne demek?
- 51 Siz topluma karşı sorumluluğunuz olduğunu düşünüyor musunuz? / Evetse, bunlar nelerdir? Sizce yerine getirebiliyor musunuz? / Hayırsa, neden?
- 52 Yurtdışında bazı ülkelerde rehber köpeklerin görme engellilerin hayatlarını çok kolaylaştırdığını biliyor muydunuz? Sizce burada da rehber köpekler yaygınlaşmalı mı?
- 52.1 Dünyada görme engellilerin hayatlarını kolaylaştıran ama bizde olmayan duyduğunuz başka şeyler var mı?
- 53 Üzerinde durulması gerektiğini düşündüğünüz, belirtmek istediğiniz başkaca bir konu var mı?

B. APPROVAL OF THE METU HUMAN SUBJECTS ETHICS COMMITTEE

UYGULAMALI ETİK ARAŞTIRMA MERKEZİ
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11 MAYIS 2018

Konu: Değerlendirme Sonucu

Gönderen: ODTÜ İnsan Araştırmaları Etik Kurulu (IAEK)

İlgil: İnsan Araştırmaları Etik Kurulu Başvurusu

Sayın Doç.Dr. Fatma Umut BEŞPINAR AKGÜNER

Danışmanlığını yaptığınız yüksek lisans öğrencisi Fatma Güneş AKŞEHİRLİOĞLU' nun "Fiziksel engellilerin deneyimlerinden hareketle engelliğin görünmezliği" başlıklı araştırması İnsan Araştırmaları Etik Kurulu tarafından uygun görülerek gerekli onay 2018-SOS-073 protokol numarası ile 11.05.2018 - 30.07.2018 tarihleri arasında geçerli olmak üzere verilmiştir.

Bilgilerinize saygılarımla sunarım.


Prof. Dr. Ş. Halil TURAN
Başkan V


Prof. Dr. Ayhan SOL
Üye


Prof. Dr. Ayhan Gürbüz DEMİR
Üye


Doç. Dr. Yaşar KONDAKÇI
Üye


Doç. Dr. Zana ÇITAK
Üye


Doç. Dr. Emre SELÇUK
Üye


Dr. Öğr. Üyesi Pınar KAYGAN
Üye

C. TURKISH SUMMARY / TRKE ZET

Engellilik sosyal olarak inřa edilen bir olgudur. Fiziksel veya ruhsal bir sakatlıęa toplumsal olarak yklenen anlamlar, bu durumu yařayanlara iliřkin anlayıř ve varsayımlar, engellilere yaklařım ve davranıřları belirlemekte ve toplumsal olarak yařanan engellilięi oluřturmaktadır. Bu nedenle, bir toplumun kltrel ve sosyal engellilik anlayıř ve algısı, hem bire bir iliřkilerde hem de kavramsal baęlamda insanların engellilere ynelik tepkilerinin ve davranıřlarının temelini oluřturmaktadır. Bařka bir deyiřle, sosyal ve kltrel faktrler aynı toplumda yařayan engelliler, aileleri, okullarındaki kiřiler, iřyerlerindeki alıřanlar, sokaktaki insanlar ve devleti idare edenlerin engellilere yaklařımını belirleyen temel unsurlardır. Dolayısıyla, engellilerin toplumsal yařamdaki konumu ve yařam kalitesi, toplumun engellilik algısı ve anlayıřı, yaklařımı, bakıř aısı ve davranıřları ile doęrudan ilintilidir. nk aileden devlete tm toplumsal kurum ve kiřilerin engellilik sorunlarıyla ilgili yaptıkları, engellilięe ynelik toplumsal bakıř aısı, ilgili kltrel kodlar ve engellilere iliřkin varsayımlar erevesinde řekillenecek ve bunlardan kaynaklanacaktır.

Toplumda engellilerle ilgili yrtlen alıřmalarda eliřkiler ve tutarsızlıklar bulunmakta, bu nedenle verimli ve etkili sonular alınamamaktadır. Bu durumu toplumun hemen her kesiminin faaliyetlerinde yaygın olarak grmek mmkndr. řyle ki; Bugn Trkiye'de engellilięe iliřkin yasal dzenlemelerin pek ok aıdan olduka kapsamlı olduęu belirtilmektedir(itil & nc, 2018; Gkek-Karaca, 2019; řiřman, 2011; Tansuę, 2009). Ancak bu dzenlemelerin uygulanmasındaki sorunlar, engellilik literatrnde en ok tartıřılan konulardan biridir(Aysoy, 2004; Aysoy, 2008; Azarkan & Benzer, 2018; Bezmez, 2013; aęlar, 2011; itil & nc, 2018; Erten & Aktel, 2020; TOHAD, 2015). Toplumda engellilik konusunda bir hassasiyet olduęu ve insanların gndelik yařam iinde engellilere olumlu yaklařtıęı dřnlmektedir. Buna karřın, her yz kiřiden onikisi engelli olmasına raęmen(SIS, 2002), engelliler gerekte var oldukları oranda toplumsal yařam iinde grlmemektedirler. zel eęitim merkezlerinin yanısıra okullarda uygulanan kaynařtırma eęitimi sayesinde, engelli ocukların da eęitim hakkından yararlandığı sylense de, engellilerin %60'ı daha ortaokulu tamamlamadan okulu bırakmaktadırlar(UNESCO, 2017). Pozitif ayrımcılık dzenlemeleri ile engelli istihdamında artıř olduęu belirtilse de, engelli nfusun iřgcne katılım oranı toplamda %22,1'dir(EYHGM, 2020) ve alıřma olanağı bulan engelli genlerin iřyerlerindeki mutsuzluęu gzardı edilmektedir. Ailelerin, engelli aile yelerinden sorumlu oldukları ve onlara herkesten iyi bakacakları ngrlrken, aynı zamanda ailelerin farkındalık eksiklięi ve bilinlendirilmeleri gereklilięi literatrde en ok vurgulanan konulardandır. Engelliler, toplumun kltrel ve toplumsal anlayıřı doęrultusunda yařamlarını srdrmektedirler, oysa toplumun birer yesi olmalarına raęmen onların deneyimlerinin topluma entegrasyonunda byk bir kltrel bořluk vardır.

Sonuç olarak, engelliler, aileleri, eğitim ve iş yaşamları, toplum ve hatta devlet uygulamalarında kendini gösteren bu tutarsızlık ve verimsizliğin ortak özelliği, bu kesimlerde teoriyi pratiğe dönüştüren, yani uygulamayı yapan kişilerin aynı toplumun üyeleri olmalarıdır. Bu durumda, toplumun her kesiminden insanın hayata geçirdiği engelliliğe yönelik sosyal ve kültürel algı, anlayış ve bakış açısı bu verimsizliğin ve etkisizliğin temel nedenlerinden biri olmalıdır. Ayrıca, engellilerin görünmezliği ile bu sorunlu sonuçlar arasında doğrudan bir ilişki olabileceği de gözardı edilmemelidir.

Toplumsal yaşamda engellilik konularındaki tutarsızlığın, verimsiz ve etkisiz uygulamaların birbirleriyle ilişkili sosyal, kültürel, ekonomik, politik, idari, ailevi ve kişisel sebep ve sonuçları olabilir. Ancak bu çalışmada, sosyal ve kültürel sebeplere odaklanılmıştır. Dolayısıyla, bu çalışmanın amaçlarından biri, engellilerin deneyimlerinden hareketle, Türkiye’de toplumun engellilik ile ilgili konularda temel sosyal ve kültürel bakış açılarını, anlayışlarını ve yaklaşımlarını araştırmaktır. Çünkü, son on yılda bir ivme kazanmış olsa da, engellilik Türkiye’de sosyal bilimlerde en az çalışılan konulardan biridir. Yanısıra, ilgili literatürde çoğunlukla engellilik sorunları çalışılmaktadır ancak bu sorunların kültürel ve toplumsal kaynaklarının, özellikle engellilerin deneyimlerinden hareketle ve etnografik metodlarla araştırılmasında ciddi bir boşluk bulunmaktadır. Çalışmanın diğer amacı da, engellilerin deneyimlerinin akademiye ve topluma aktarılmasına katkıda bulunmaktır. Bu bağlamda araştırmanın ana sorusu şudur; Engellilik sorunlarına ilişkin bireysel ve kurumsal uygulamaların yetersiz ve etkisiz olmasının temel sosyal ve kültürel nedenleri nelerdir?

Temel sosyal ve kültürel nedenlerin araştırılması son derece geniş ve çok katmanlı bir konudur. Bu nedenle bu araştırma, engellilerin görünmezliği kavramı ve saha çalışmasına katılanlar ile sınırlıdır. Toplumun engelliliğe yaklaşımı, toplumun birer ferdi olan engelliler tarafından da içselleştirilmektedir. Aynı zamanda engelliler, doğal olarak bu konuda en fazla bilgi ve deneyime sahip kişilerdir. Ayrıca, son derece karmaşık ve geniş bir alan olan engelliliğe ilişkin toplumsal yaşamdaki deneyimler engel kategorisine göre farklılık gösterebilmektedir. Bu nedenlerle bu çalışma, üniversite eğitime devam eden veya üniversiteye giriş sınavına hazırlanan görme engelli genç bireyler ile yapılmıştır. Alan çalışmasından önce çalışmanın genel çerçevesi belli olsa da, asıl amaç, görme engellilerin gündelik yaşam deneyimlerini anlayabilmek ve böylece toplumsal gerçekliği olabildiğince sınırlama olmadan kavrayabilmek idi. Bu amaçla araştırma metodu olarak katılımcı gözlem ve derinlemesine görüşme teknikleri seçilmiştir.

Katılımcı gözlem süreci, Ankara’da kar amacı gütmeyen bir dernek olan Orta Doğu Engelsiz Eğitim Derneği[ODED]’nde gönüllü öğretmenlik yaptığım sekiz aylık süreci kapsamaktadır. Görme engelli gençlere üniversite sınavına hazırlanmalarında destek olan ODED’de bulunduğum süreçte, 18-22 yaş aralığında, sekiz görme engelli kişi (üç kadın, beş erkek) kurslara katılıyordu. Öğrencilerden dördü kör, yani kendi aralarında “total” dedikleri, tamamen işlevsel görme bozukluğu veya sadece ışık algısına sahip bireylerdi. Diğer dördü ise az gören, yani en az yüzde 40 ve üzerinde işlevsel görme bozukluğu olan gençlerdi. Görme engelli öğrencilere felsefe grubu derslerinde öğretmenlik yapmanın yanısıra, onlarla birlikte alışveriş yapma, dernek içinde ve dışında piknik, kutlama gibi bazı

etkinliklere katılma fırsatım oldu. Bu süreçte ayrıca, bazı öğrencilerin anne, baba ve kardeşleri, sıklıkla ziyarete gelen derneğin eski öğrencileri, diğer gönüllü öğretmenler ve dernek yöneticileri ile de zaman geçirme imkanım oldu.

Görme engelli gençlerin hayatlarının önemli bir dönüm noktasında gündelik yaşamlarına katılmamı sağlayan katılımcı gözlem süreci, onları ve yaşadıklarını mümkün olduğunca anlamamı sağladı. Ayrıca birbirleriyle, yakın çevreleriyle ve genel olarak toplumla olan iletişimlerini gözlemledim. Bu nedenle bu süreçte, günlük hayatın rutininde fark edilemeyen ancak görme engelli gençler için önemli ve belirleyici olan kültürel bakış açılarını ve toplumsal yaklaşımları yakalama şansım oldu. ODED’de öğretmenlik yapmaya başlamadan önce ailemde veya yakın çevremde herhangi bir görme engelli kişi ile iletişimim olmamıştı. Bu nedenle bu deneyim, onların gündelik yaşamlarına dışarıdan ve daha geniş bir pencereden bakmamı sağladı. Ancak, aynı zamanda öğretmenleri olarak onlarla yakın iletişimde olmak, belirttikleri konuların kişisel nedenlerden mi yoksa engellilik ile ilgili toplumsal kabullerden mi kaynaklandığını anlamama olanak verdi. Kısaca katılımcı gözlem, gündelik yaşam içinde görme engelli olanlar ile olmayanların benzerliklerini, farklılıklarını ve insanların tepkilerini gözlemlememi, görme engelli gençler için belirleyici olan toplumun farklı kesimlerinde ortak kültürel ve toplumsal yaklaşımları, anlayışları ve varsayımları yakalamamı sağladı.

Yarı-yapılandırılmış derinlemesine görüşmeler, Ankara’da yaşayan, 18-23 yaşları arasında, üniversite öğrencisi veya üniversite sınavına hazırlanan, dördünün aynı zamanda bir devlet dairesinde çalıştığı, 15 görme engelli (dokuz kadın, altı erkek) birey ile yapılmıştır. Görüşmecilerin yedisi kör olduklarını, diğerleri ise az gören olduklarını belirtmişlerdir. Görüşülen kişilerden altısı ODED’de öğretmenlik yaptığım öğrenciler, diğer dokuzu ise onların arkadaşları veya eski ODED kursiyerleri idi. Hepsisi bekar olan ve aileleri ile yaşayan görüşmecilerden, ikisi kiracı olduklarını, dördü ailelerinin ev ipoteki ödemeye devam ettiği evlerde, biri kendi gecekondularında ve sekizi de kendi evlerinde yaşadıklarını belirtmişlerdir. Bütün görüşmeciler aile gelirlerinin asgari ücretten yüksek olduğunu belirtmiş, 13’ü aile gelirini ortalama, biri ortalamanın altında ve biri ortalamanın üstünde olarak tanımlamıştır. Katılımcılara, kişisel bilgiler, günlük yaşam, eğitim hayatı, aile ve akrabalar, çalışma hayatı, sosyal yaşam, engellilik algısı ve tanımı, devlet, sivil toplum kuruluşları ve toplum konularında, 53 açık uçlu soru ve bazılarının alt sorularının yanısıra, her konu ile ilgili görme engellilik dışında başka engeli olan kişilerle ilgili bilgi ve deneyimleri de sorulmuştur.

Katılımcı gözlem ve derinlemesine görüşmeler ile, toplumun engellilere ilişkin temel anlayış ve yaklaşımına ulaşmak için katılımcıların anlattıkları ve deneyimleri çok geniş bir kapsamda analiz edilmiştir. Engellilik, aile, eğitim, iş yaşamı, toplum ve devlet alanlarında üzerinde durulan konuların ortak nedenleri, görme engelli genç katılımcılar için önemli ve belirleyici olan faktörler ışığında belirlenmeye çalışılmıştır. Dolayısıyla bu araştırmada etnografik yöntemlerle elde edilen veri, bulgu ve analizlerin engellilik çalışmalarına, sosyal bilimlere ve topluma katkı sağlaması umulmaktadır.

Günümüzde engellilik çalışmalarının çok daha kapsamlı ve kapsayıcı bir dönemde olduğunu belirtebiliriz. Çünkü, farklı kültürel anlayışların engellilik üzerindeki etkileri, hem sosyal model üzerine eklenen farklı bakış açılarıyla, hem de eleştirel yaklaşımla incelenmektedir. Bu çalışmanın kavramsal çerçevesini oluşturan da bu yaklaşımdır. Konuyu kısaca açıklamak gerekirse; Ana akım engellilik çalışmaları, 1970’lerde, İngiltere merkezli engelli hakları hareketi ile birlikte medikal modele karşı Anglo-Amerikan bakış açısıyla ortaya çıkmış olan sosyal model ile gelişmiştir. Öncesinde engellilik politikalarına hakim olan medikal modele göre, “sorunun kaynağı engelli kişidir”(Oliver, 2004:20) ve bu doğrultuda engelliliğe yalnızca tedavi veya rehabilite edilmesi gereken bir olgu olarak yaklaşma eğilimi hakimdir. Yanısıra engellilik, 1981 yılının Birleşmiş Milletler tarafından Uluslararası Engelliler Yılı olarak ilan edilmesinden sonra, küresel kamuoyu söyleminde de bir insan hakları sorunu olarak gündeme gelmeye başlamıştır(Meekosha & Shuttleworth, 2009).

Ancak sosyal model, özellikle 2000’li yıllara gelindiğinde, bedeni, sakatlığın etkilerini ve deneyimlerini görmezden geldiği, sosyal hayattaki engelliliğin dünyanın farklı bölgelerindeki farklı yaşam tarzları dikkate alınmadan, sadece modelin ortaya çıktığı bölge bağlamında değerlendirdiği, yanısıra, cinsiyet, ırk, yaş gibi çoklu dezavantajlardan kaynaklanan baskıları hesaba katmadığı için eleştirilmeye başlanmıştır. Ayrıca bu dönemde, sosyal model eleştirilerine paralel olarak genişleyen engellilik çalışmalarına, küresel güneyden yapılan çalışmalar da eklenmeye başlamıştır(Meekosha & Shuttleworth, 2009). Böylece hem sosyal modeli eleştiren hem de eksikliklerini vurgulayan, dolayısıyla konuya daha kapsamlı ve farklı bakış açıları öneren Eleştirel Engellilik Çalışmaları(Critical Disability Studies) ön plana çıkmaya başlamıştır(Ginsburg & Rapp, 2020). Dolayısıyla günümüzde engellilik çalışmaları, hem sosyal modelle şekillenen öncül çalışmaların üzerine inşa edilmeleri(Meekosha & Shuttleworth, 2009) nedeniyle, hem de eleştirel engellilik çalışmaları ile farklılıkları da kapsayarak, olgunlaşan bir alandır(Dan Goodley et.al, 2019).

Türkiye’de engellilik faaliyetleri ve çalışmaları büyük ölçüde devlet insiyatifiyle yönlendirilmektedir. Özellikle 2000’li yıllardan itibaren uygulanmaya başlayan sosyal politikalar, beraberinde çıkarılan kanun ve yönetmelikler çerçevesinde, devlet girişimlerine paralel olarak ülkede engelli çalışmaları ivme kazanmıştır. Yani, yasal düzenlemeler aileden eğitime hemen her toplumsal kurumun konuya yaklaşımını, dolayısıyla bireylerin gündelik yaşamını etkilemektedir. Bu nedenle bu konudaki gelişmeleri belirtmek hem bu çalışmanın ilerlediği zemini hem de araştırmanın amacını pekiştirmek açısından yararlı olacaktır.

1950’lerde devlet insiyatifi ve kişisel çabalarla, bugünkü bilinen adıyla Altı Nokta Körler Derneği ve Türkiye Sakatlar Derneği gibi derneklerin kurulmasından sonra, 1980’lerden itibaren çok daha sistematik ve kurumsal düzeyde ilerlemeler sağlandığı söylenebilir. 1999 yılında Özürlüler İdaresi Başkanlığı tarafından yürütülen 1.Özürlüler Şurası’nda alınan kararların önemli katkılarından, 2005 yılında Engelliler Yasasının yürürlüğe girmesiyle eğitim, istihdam, sosyal güvenlik gibi pek çok alanda yasa ve yönetmelikler güncellenmiş ve engelli hakları konusunda önemli gelişmeler sağlanmıştır(Burcu, 2015; Yılmaz, 2014). Sosyal politika düzenlemelerine ilişkin bu

gelişmeler, Avrupa Birliği ile 2005 yılında başlayan tam üyelik müzakereleri, ve 2006 yılında Birleşmiş Milletler Engelli Hakları Sözleşmesi'nin kabulü ile paralellik göstermektedir.

Türkiye'de resmi olarak uygulanan sosyal modelin(ÖZİDA, 2010) en önemli kazanımlarından biri, engellilerin yaşam kalitelerinin iyileşmesi için elzem olan hak temelli yaklaşımdır. Bu doğrultuda, yeterliliği ayrı bir tartışma konusu olmakla birlikte, engellilerin ekonomik kazanımları konusunda bir parantez açmak gerekiyor. Çünkü, tarihsel olarak yoksullukla ilişkilendirilen engelliler için, özellikle 2000'li yıllardan sonra, hem doğrudan parasal destekler (sosyal yardım, engelli maaşı) hem de dolaylı finansal destekler (iş ve emeklilik imkanları, eğitim, sağlık ve ulaşım hizmetleri, vergi muafiyetleri vb.) engellilerin yaşamlarında gözle görülür iyileşmeler sağlamıştır(Ak, 2019; Yılmaz, 2014). Ancak, bütün bu olumlu gelişmelere rağmen, sosyal modelin ve hak temelli yaklaşımın toplumsal yaşamda içselleştirilemediğini, hatta insanlar tarafından yeterince benimsenmediğini, dolayısıyla uygulama sorunlarının olduğu vurgulanmaktadır(Aysoy 2004, 2008; Azarkan & Benzer, 2018; Bezmez, 2013; Bezmez & Yardımcı, 2013; Çağlar, 2011; Çitil & Üçüncü, 2018). Benzer şekilde, yapılan araştırmalar engellilerin eğitimi konusunda da uygulamada beklenen sonuçların elde edilemediğini göstermektedir(Bayhan & Sipal, 2011; Çakıroğlu & Melekoğlu, 2014; Çitil, 2009; Demirtaş, 2019; İşlek, 2016; Sakız & Woods, 2014; Şenel, 1998; Şirin, 2019; TOHAD, 2015). Burada sadece resmi düzenlemeler değil, diğer tüm tarafların, yani okul yöneticileri, öğretmenler, danışmanlar ve ailelerin engellilerin eğitimine yönelik uygulama ve yaklaşımlarının da tartışıldığını belirtmek gerekiyor(Ereş & Canaslan, 2017; İşlek, 2016; Melekoğlu, 2014; Sakız & Woods, 2014; Yılmaz, 2015). Bu çalışmada üzerinde durulan eğitim, gündelik yaşam becerileri ve bağımsız hareket becerileri eğitimleridir. Çünkü, ilerleyen bölümlerde açıklanacağı üzere, “kendine yeterli olma hali” toplumsal olarak engellilere yaklaşımı doğrudan etkilemektedir.

Yaygın inanın aksine, görme engellilerde duyma, koklama gibi duyuların kendiliğinden gelişkin olduğuna dair güvenilir bilimsel verilere ulaşılamamıştır. Ancak Enç ve arkadaşlarının(akt. Demir & Şen, 2009:155) belirttikleri gibi, “Körlerin sağlam kalan duyuları, görenlerinkine göre duyarlılık açısından herhangi bir üstünlük göstermemektedir. Söz konusu olabilecekleri tek üstünlükleri, bu duyular yoluyla aldıkları uyarıları yorumlamakta edindikleri tecrübelerdir.” Bu nedenlerle, görme engellilerin güvenli ve bağımsız yaşayabilmeleri için hem günlük yaşam hem de bağımsız hareket becerileri eğitimi almaları gereklidir. Bağımsız hareket eğitimi, görme engellilerin en az yardımla veya yardımsız olarak yön belirleme ve hareket etme becerisini sağlayan tekniklerdir. Yürüme, baston teknikleri, sesin kaynağını bulma, koku alma duyusunu kullanma vb. içerir(Altı Nokta Körler Vakfı, 2016; Körleri Eğitim ve Kalkındırma Derneği, 2021; Köşeler, 2021; MEB, 2008). Gündelik yaşam becerileri, makul düzeyde sağlık ve güvenlik sağlamak için düzenli olarak yapılması gereken yeme içme, kişisel hijyen gibi öz bakım faaliyetleridir(Materialist & Gray, akt. Altunay-Arslantekin, 2015).

Katılımcılar, ilköğretim hayatları boyunca gündelik yaşam ve bağımsız hareket beceri derslerinin seçmeli olduğunu, ve çoğunluğu, ailelerinin hem vakit kaybı olduğunu düşünmeleri hem

de “yapamayacakları”, dolayısıyla kötü birşey olabileceği korkusu nedeniyle okulda bu eğitimi almadıklarını belirtmişlerdir. ODED’de öğretmenlik yaptığım tamamen görme engelli öğrencilerden sadece birinin bağımsız hareketi vardı, diğer üçü derneğe ailelerinin yardımıyla gidip geliyor, ve örneğin kendilerine sıcak içecek hazırlayamıyorlardı. Görüşmecilerden ilkokulu yatılı okumuş olanlar, kendilerinden büyük öğrencilerden bazı gündelik yaşam beceri eğitimlerini almışlar, ancak bütün katılımcılar içinde sadece biri, bütün bağımsız yaşam becerisi eğitimlerini, ailesinin ve sınıf öğretmeninin desteği ile, zamanında aldığını belirtmiştir. Diğerleri, ancak yetişkin olduklarında ve ailelerini ikna edebildikleri ölçüde özel eğitim merkezlerinde ilk eğitimi aldıktan sonra, arkadaşlarının desteği ile bağımsız hareket becerilerini geliştirdiklerini söylemişlerdir. Burada tüm katılımcıların, çoğu doğuştan olmak üzere, çocukluklarından beri görme engelli olan genç yetişkinler olduklarını hatırlatmak gerekiyor. Hepsinin ortak görüşü, gündelik yaşam ve bağımsız hareket becerileri eğitiminin zamanında yani çocukluk döneminde alınması gerektiğidir. Bu eğitimi zamanında almadıkları için gündelik yaşamlarında gören akranları kadar pratik olamadıklarını sıklıkla belirtmişlerdir.

Engellilerin eğitimi için belirlenen politikalar ve tüm paydaşların (engelliler, ailelileri, eğitimciler, okul yöneticileri, karar vericiler) bu konuda yaptıkları, toplumun engelliliğe yönelik tutumu ve engellilerin içinde yaşadıkları toplumdaki konumları hakkında çok temel bilgiler sunmaktadır. Tarihsel olarak Osmanlı döneminde, 19. yüzyıla kadar engellilere, yoksullarla birlikte, sağlanan sosyal destek, hayırseverliğe dayalı toplumsal dayanışmanın en eski kurumlarından biri olan Vakıflar tarafından yürütülmüştür (Sağlam-Tekir, 2016; Şimşek, 2017). Bu dönemde, genel olarak engelliliğin bir kader olduğuna inanıldığından, devlet görme engellilerin eğitimi, rehabilitasyonu ve istihdamı konusunda bir politika geliştirmemiştir (İçli, 2021). Toplumun genel yaklaşımını ise eğitimci ve tarihçi Gündüz (2014) şu şekilde ifade etmiş;

Osmanlı toplumunun hayat tarzını, gelenek ve İslâm şeriatı tayin ederdi. Bu bakımdan farklı bedensel ve zihinsel kusurları olan insanlar için hem Türk kültürünün geleneksel pratikleri, hem de İslâm’ın vaz ettiği hükümler geçerliydi... Osmanlı/Türk toplumunda, engelli insanlara ayrı bir önem verilmiştir. Daha çok acıma hissinin tesiriyle, toplumda hemen herkes onlara yardımcı olmuştur (p.6-7).

Benzer şekilde, bu araştırmanın bulgularına göre de, engelliler toplumsal yaşamda her koşulda yardıma ihtiyaç duyan kişiler olarak görülmektedirler. Çünkü, derinlemesine görüşmelerde sorulan sorular yardım konusu ile ilgili olmamasına rağmen, katılımcıların farklı konulardaki cevaplarının çoğu yardım kavramı etrafında şekillenmiştir. Öyleki “yardım” en çok telaffuz edilen kelimelerden biri olmuştur. Katılımcılara göre, sokakta, okulda, ailede ve hatta devlet tarafından yardım almamak söz konusu değildir. Bu durum o denli içselleştirilmiştir ki, görme engelli gençler için sorun, insanların doğru şekilde nasıl yardım etmeleri gerektiğini bilmemeleridir. Bu nedenle, araştırmaya katılanların deneyimlerinden hareketle, toplumda, engellilere yardım etme davranışının toplumsal yaşamın bir gereği ve kültürel anlamda neredeyse engellilerin “doğal bir hakkı” olarak görüldüğü sonucuna varılmıştır.

İlk bakışta toplumun engellilere yardım etme yaklaşımının görme engellilerin hayatını kolaylaştırdığı için bir sorun olmadığı, aksine memnun olunması gereken bir durum olduğu düşünülebilir. Nitekim, örneğin, erişilebilirlik sorunları da dikkate alındığında, sokakta mutlaka yardım edecek birilerinin olacağı düşüncesi, bazı katılımcıların dışarı çıkma motivasyonunu arttıran en önemli etkenlerden biriydi. Ancak katılımcıların, bu konuda çoğunlukla olumlu yorumlar yapmadıklarını, tam tersine daha çok yardım ederken yapılan hatalara odaklandıklarını fark ettim. Görüşmeler derinleştikçe, sorunun kaynağının, toplumda var olan engellilere yardım etme halinden değil, bu davranışın büyük ölçüde “engelliler yapamaz” algısından kaynaklanması olduğu ortaya çıktı. Katılımcıların bu konudaki açıklamalarını özetlemek gerekirse, yardım, en çok acıma, farklı yaşam biçimlerini bilmeme, özel hayatın gizliliğine saygısızlık ve yardımın doğası gereği yardım eden ile alan arasında kendiliğinden oluşan, hiyerarşi sarmalında kendini göstermektedir. Bu durumda yapılanın destek olduğunu söylemek zor olsa da, engellileri toplumun bütününden ayırdığını söylemek yanlış olmayacaktır. Bu noktada olumlu sonuç vermesi beklenen yardım, engellilerin hayatında bir çelişki haline gelmektedir. Çünkü, mesele sadece, örneğin, sokakta engellilere nasıl davranıldığı değil, toplumda yerleşik “engelli yapamaz” algısından kaynaklanan, ve sadece yardım etmeye dayanan bu anlayışın, engellilerle ilgili hemen tüm faaliyetlere yön vermesidir. Katılımcıların deneyimlerinden hareketle örneklendirmek gerekirse bu anlayış, kanun koyucuların engelliliğe yaklaşımını, öğretmenlerin motivasyonlarını, iş yerlerinde çalışanların yaklaşımını, sokaktaki insanın tutumunu, ailenin engelli aile bireyinin yaşamı ile ilgili kararlarını, ve hatta engelli bireyin engellilik algısını şekillendirmektedir.

Görme engelli gençlerin günlük yaşamlarına katıldığım süreçte edindiğim deneyim ve gözlemlere, yanısıra derinlemesine görüşmelerde ulaşılan bulgular ışığında, toplumda engellilere yardım etmeye dayalı anlayış ve uygulamaların özellikleri şu şekilde sıralanabilir;

- köklü sosyal ve kültürel temelleri vardır
- engellilerin doğal bir hakkı olarak halk tarafından içselleştirilmiştir,
- engellinin hiçbir durumda yapamayacağı varsayımından kaynaklanır
- yardım etmekten başka yapılabilecek bir şey olmadığına dair toplumsal anlayışa dayalıdır.
- toplumda yaygındır
- toplumun farklı kesimleri tarafından uygulanmaktadır(engelliler, aileleri, okul ve eğitim hizmetlerindeki insanlar, devlet görevlileri, sokaktaki insanlar)
- gündelik yaşamda geçici kolaylıklar sağlar,
- kalıcı iyileştirmelere yer bırakmaz
- yaşam kalitesinin yükselmesine engel olur

Çalışma esnasında toplumda böylesine ortak, yaygın ve engellilerin yaşamlarını etkileyen bir anlayışın, ve bu anlayıştan kaynaklanan pratiklerin yukarıda sıralanan temel özelliklerini içeren bir kavramla ifade edilmesi gerekliliği ortaya çıkmış, ancak mevcut engellilik literatüründe inceleme fırsatı bulduğum kavramlar bu temel özellikleri karşılamamıştır. Bu nedenle bu anlayış ve

beraberindeki uygulamaları, engellilerin gündelik yaşamında geçici de olsa kolaylık sağlayan yardım etme eyleminden ayırt etmek için önerdiğim kavramsallaştırma, “sadece-yardım yaklaşımı”dır.

Sadece-yardım yaklaşımı, engellilere kalıcı olmayan, anlık kolaylıklar sağlayan her türlü faaliyeti yaratan toplumsal anlayışı ve bu anlayıştan kaynaklanan pratikleri ifade eder. Bu yaklaşım, işlevselliğin mümkün olamayacağı algısına dayandığından, yardım edilen kişinin işlevselliğine katkı sağlamaz. Çünkü, ne yapılırsa yapılsın, engellileri zihinsel ya da bedensel engelleri nedeniyle yetersiz kabul eden bir önyargı içermektedir. Dolayısıyla sadece-yardım yaklaşımına göre, engelliler ile ilgili yapılabilecek tek şey onlara yardım etmektir. Yaklaşım, en başından engellilerin kendilerine yetebilen bireyler olabilme seçeneğine yer bırakmadığından, engellilikle ilgili yapılanların verimsiz ve etkisiz sonuçlarına neden olmaktadır. Toplumda hakim olan sadece-yardım yaklaşımı nedeniyle, örneğin, farklı eğitim teknikleriyle kendi kendine yeterlilik sağlama seçeneği aileler tarafından fark edilememekte, çevresel erişilebilirliği düzenleme mantığı toplumda anlaşılamamakta ve hak temelli yasalar etkin bir şekilde uygulanamamaktadır. Bunların sonucu olarak, sadece-yardım yaklaşımı toplumsal yaşamda engellileri muhtaç ve görünmez olarak inşa etmektedir.

Katılımcıları en çok rahatsız eden konulardan bir diğeri de, toplumda “muhtaç” olarak algılanmalarıdır. (Bu çalışmada muhtaçlık, kendi kendine yeterli olamama halini ifade etmektedir.) Sadece-yardım yaklaşımının bir sonucu olarak, “muhtaç engelli” varsayımı toplumda olduğu gibi engellilerin kendilerinde de sürekli pekiştirilmektedir. Bu durumu somut olarak açıklamak için beyaz baston kullanımı ve algısı örnek olarak verilebilir.

Bağımsız hareket becerisi kazanmanın görünen en pratik yolu, beyaz baston kullanımı olmasına rağmen, ODED’dekilerin çoğunluğu baston kullanmıyorlardı. Katılımcılara göre bunun sebepleri; muhtaç olarak etiketlenmemek, sağladığı kolaylıkların farkında olmamak, zamanında beyaz baston eğitimi almamış olmak, bağımsız hareket etmenin gerekliliğini ve bağımsız yaşamının mümkün olduğunu kavramamış ailelerin baskısı, engelli kişi ve ailelerin beyaz baston kullanmanın kendi kendine yeterliliğe katkısını kabullenmemeleri, çevresel erişim engelleri ve toplumda beyaz bastonlu birisini görünce ne yapılması gerektiğinin bilinmemesi.

Sonuç olarak, bir yerden bir yere gitmek için bir başkasının yardımına gereksinim duyulması pahasına, beyaz baston kullanılmıyor ve “görme engellilerin kendi kendine yeterli olamayacağı” algısı, toplumda olduğu kadar engellilerde de pekiyor. Adeta engelli olmanın varsayılan doğası gereğiymiş gibi, engelliliğin muhtaçlık ile özdeşleştirilmeye devam ediyor olması engellilerin yaşam kalitesini düşürmektedir. Çünkü, görme engellilerin ihtiyaçlarını karşılayabilmeleri için kaçınılmaz olarak başkalarına ihtiyaç duydukları varsayıldığından, engellilerle ilgili tüm yapılanlar (ve yapılmayanlar) buna göre yürütülmekte, ve sonuç olarak etkisiz ve verimsiz sonuçlar alınmaktadır. Dolayısıyla muhtaç engelli varsayımı, sadece-yardım uygulamalarını güçlendirmektedir. Ve, toplumsal yaşamın birbirini sürekli etkileyen ve yeniden üreten dinamikleri sonucunda, tıpkı bir kısır döngü gibi, sadece-yardım yaklaşımı da muhtaç engelli varsayımını güçlendirmekte ve yeniden inşa etmektedir.

Bu kısır döngü, daha derin olarak incelendiğinde, aslında araştırmanın ön saha çalışmalarında başlarında fark edilen engellilerin görünmezliği yeniden kendini göstermiştir. Engellilerin görünmezliği bu çalışmada, hem somut hem de metaforik anlamında kullanılmaktadır. Şöyle ki, engelliler, fiziksel olarak toplumsal yaşama dahil olmadıkları için toplumsal hayatta görülmemektedirler. Aynı zamanda, engelli bireyler, oldukları gibi değil, engelliliğe ilişkin kalıpyargılar ve önyargılarla değerlendirildikleri için, toplum tarafından tanınmazlar ve kendi gerçekleriyle fark edilmezler. Ayrımcılığa yol açan olumsuz kalıpyargılar ve önyargılar, fiziksel veya ruhsal bir sakatlığı fiilen engelliliğe dönüştüren ve tüm dünyada yaygın olarak yaşanan temel kavramlardır. Kültürel farklılıklar ise, toplumdaki olumsuz kalıpyargıların, önyargıların ve ayrımcılığın nasıl yaşandığını, hatta günlük hayatta nasıl yeniden üretildiğini ortaya koymaktadır.

Bu çalışmada aktarılan deneyimler, toplumda genel olarak, engelli insanların yaşamlarının farkında olmama nedeniyle, ciddi bir bilgi eksikliği olduğunu, eğer bir farkındalık olsa bile bunun çoğunlukla engellilerin yaşadığı varsayılan “kişisel trajediler” çerçevesinde oluşan yanlış bilgi ve kavramlarla şekillendiğini göstermektedir. Bu çıkarımlar çalışmadan elde edilen bulgular ışığında şu şekilde özetlenebilir; Bu araştırmanın ön saha çalışmalarında görüşülen kişiler de dahil olmak üzere, bütün katılımcıların, başka insanlardan kaynaklanan yaşadıkları herhangi bir problemin sebebi sorulduğunda verdikleri ilk cevap hemen hemen aynı olmuştur, “çünkü insanlar bilmiyorlar, önceden biz de bilmezdik/benden önce ailem de bilmezmiş”.

Buna ek olarak, görme engelli görüşmecilere, her temel konu başlığında, yaşadıkları herhangi bir durumu başka türde engelleri olanların da yaşayıp yaşamadığı sorulmuştur. Bu sorulara verilen cevaplar, ya bilmiyorum olmuştur, yada yetersiz olduğunu varsaydıkları başka engelleri olan kişiler ve onlar için yapılması gerekenler hakkındaki kalıpyargılar, kişisel inanç ve hisleri olmuştur. Hatta kendileri hakkında yanlış olduğunu düşündükleri bazı önyargıları, söylemleri veya kulaktan dolma bilgileri başka engelliler için söyleyenler de olmuştur. Bu da bizi diğer bulguya getiriyor, toplumda engellilerle ilgili yanlış bilgi ve kavramlar hakimdir, çünkü toplumda engelliler hakkında bir dereceye kadar bir farkındalık varsa bile, bu çoğunlukla engellilerin yaşadığı farzedilen kişisel zorluklar çerçevesinde oluşan bir tür farkındalık, yani yanlış bilgi ve kanılara dayanmaktadır.

Bu konudaki en somut örnek, görüşmecilerin 1990’lardan bu yana Türkiye’de idrak edilen 3 Aralık Dünya Engelliler Günü veya benzer gün ve haftalar hakkındaki tecrübeleri ve düşünceleridir. Buradan hareketle, toplumda bir dereceye kadar farkındalık yaratma çabası olarak değerlendirilebilecek Engelliler Günü’ndeki faaliyetler ve söylemler, engellilerin gerçekte yaşamlarına ve potansiyellerine vurgu yapmamaktadır. Aksine çoğunlukla, varolan klişe ve önyargıları körükleyen, insanların merhamet ve hatta acıma duyguları hedeflenmektedir. Dolayısıyla, bir anlamda engelliler toplumda “bilinmeyen” olarak kalmaya devam etmekte, ve bu da kaçınılmaz olarak önyargıları yeniden üretmekte, ve hatta ayrımcılığa yol açmaktadır. Elbette engellilerin maruz kaldığı önyargı ve ayrımcılık tek bir sebebe indirgenemez. Ancak bu araştırmanın önemli bulgularından biri de, toplumdaki bilgi eksikliğinin, yanlış kavram, kanı ve yanlış bilgilerle birlikte,

engellilere yönelik toplumsal tutumun çok önemli bir nedeni olduğunun göz ardı edilmemesi gerektiğidir.

Görme engelli genç katılımcıların deneyimlerinden hareketle bu çalışmada, engellilerle ilgili hemen tüm faaliyetlere yön veren sadece-yardım yaklaşımının, engelliler için kalıcı çözümlere yer bırakmadığından, muhtaç ve görünmez engelliler inşa ettiği sonucuna varılmıştır. Engelliler, fiziksel ve metaforik olarak toplumsal yaşamda görünmezdirler. Toplumda engelliler hakkında yanlış kavram, kanı ve bilgilerle çerçevelenmiş bir bilgi ve farkındalık eksikliği bulunmaktadır. Dolayısıyla, araştırmanın ana sorusunun cevabı; Engellilerle ilgili konularda bireysel ve kurumsal uygulamaların yetersiz ve etkisiz olmasının temel sosyal ve kültürel nedenleri, sadece-yardım yaklaşımı, muhtaç engelli varsayımı ve engellilerin görünmezliği.

Görünmezlik, kaçınılmaz olarak verimsiz ve yetersiz uygulamalara yol açarak, engellilerin yaşam koşullarının iyileştirilmesine yönelik faaliyetlerin önündeki engellerden biridir. Diğer bir deyişle, toplumsal yaşamda sürekli olarak birbirini inşa eden ve yeniden üreten, etki ve etkileşimler neticesinde, adeta bir kısır döngü gibi, engellilerin yaşam kalitesini artırmaya yönelik faaliyetlerin verimsizliği ve tutarsızlığı, sadece-yardım yaklaşımına yol açan muhtaç engelli varsayımının kaynaklarından biri olarak engellilerin görünmezliğidir.

Toplumsal yaşamda engelli bireyler görünür olmalıdır. Bu sayede toplumsal yaşamın içinde kendine yeten engelliler ile ilgili bir aşinalık oluşabilir. Bu aşinalık, engelli insanları ve ailelerini “yapabileceklerine” ikna etmenin yanı sıra, toplumda farkındalık yaratmanın en etkili yollarından biri olacaktır. Dolayısıyla, engellilerle ilgili varsayımlardan kaynaklanan olumsuz kalıpyargı ve önyargıların yeniden üretilmesine engel olunabilir. Benzer şekilde, böylesi bir aşinalık, örneğin, hak temelli kazanımların toplumu oluşturan insanlar tarafından içselleştirilip, verimli bir şekilde hayata geçirilebilmesine katkı sağlayacaktır.

Toplumsal yaşamda engellilere aşinalık gelişebilmesinin en etkili yollarından biri, bu çalışmanın da amaçlarından biri olan, engellilerin deneyimlerinin akademiye ve topluma aktarılmasıdır. Engellilerin deneyimlerinin toplum kültürüne aktarılması kültürü zenginleştirecektir. Ancak asıl katkı, toplumda yerleşik muhtaç engelli varsayımını ve sadece-yardım yaklaşımını kırma yolunda önemli bir adım olmasıdır. Aynı zamanda, engellilerin görünürliğini sağlarken, hem engellilik hem de engelliler hakkında topluma doğru bilgi aktarmanın bir yoludur. Böylelikle, engellilerin maruz kaldığı sorunlar doğru tespit edilerek, bu sorunlara etkili ve verimli çözümler üretilir.

Belki de bu sayede, toplumda yerleşik engellilik duyarlılığı ve engellilere yardım etme eğilimi, destek olma anlayışına evrilebilir. Bu yolla, engellilikle ilgili uygulamaların amacının anlık kolaylıklar yerine, mesela erişilebilirlikle ilgili kalıcı iyileştirmeler olması sağlanabilecektir. Ve belki de bu sayede, toplumda engellilere sadece-yardım yaklaşımıyla değil de, engellilerin istek ve gereksinimleri doğrultusunda, mesela, destek-tabanlı yaklaşım gelişebilir.

D. THESIS PERMISSION FORM / TEZ İZİN FORMU

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