REFLECTIONS OF SOCIAL AND CULTURAL UNDERSTANDINGS OF THE STATE AND NON-GOVERNMENTAL ORGANIZATIONS ABOUT DISABILITY: DYNAMICS OF SOCIAL EXCLUSION

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Approval of the Graduate School of Social Sciences

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ABSTRACT

REFLECTIONS OF SOCIAL AND CULTURAL UNDERSTANDINGS OF THE STATE AND NON-GOVERNMENTAL ORGANIZATIONS ABOUT DISABILITY: DYNAMICS OF SOCIAL EXCLUSION

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This thesis aims to explore the role of charity and charity based system of social policy in relation to social exclusion and disability as well as the structural and cultural factors behind charitable efforts targeting disabled people in Turkey. Within the scope of this study, social exclusion concept is accepted as a multidimensional process rather than an endpoint. Furthermore, it is argued that disabled people experience hybrid forms of exclusionary processes rooted in socioeconomic and cultural representational inequalities and charity is a critical source in worsening these processes. To understand the role and effect of charity in the dynamic relationship between social exclusion and disability, a qualitative research involving in-depth interviews with people with orthopedic disabilities and the representatives of disability related NGOs is employed. However, this study is not representative of the entire disability experience that involves heterogeneity and therefore only represents the research group. This study concludes that the relationship between charity, disability and socio-cultural exclusion in the Turkish context involves dynamics processes with interacting complex set of factors such as individualization of oppression, charity based system of social policy, legislative efforts involving discriminative treatment, medicalization of disability, the role and priorities of NGOs, cultural representation of disability, agency and the effect of religion. Moreover, it is observed that not only NGOs' but also the state's understanding about disability is dominantly shaped through charity. One of the most important conclusions of this study is that charity activities affect socio-cultural exclusionary processes experienced by disabled people through promoting strong dualism pointing two mutually exclusive groups of people as disabled and non-disabled.

Keywords: Disability, Social Exclusion, Charity, Individualization of Disability Oppression, Disability related NGOs.

ÖZ

DEVLET VE SİVİL TOPLUM KURULUŞLARININ ENGELLİLİK HAKKINDAKİ SOSYAL VE KÜLTÜREL ANLAYIŞLARININ YANSIMALARI: SOSYAL DIŞLANMA DİNAMİKLERİ

Girişmen, Gizem
Yüksek Lisans, Sosyal Politika
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Bu tez, Türkiye’de yardım faaliyetlerinin ve muhtaçlık ekseninde yardım anlayışıyla şekillenen sosyal politikaların, sosyal dışlanma ve engellilikle ilintili rolünün yanı sıra engellilere yönelik gerçekleştirilen yardım etkinliklerinin ardındaki yapısal ve kültürel etmenleri incelemeyi amaçlamaktadır. Çalışma kapsamında sosyal dışlanma, bir durum tespiti olmaktan çok, çok boyutlu bir süreç olarak kabul edilmektedir. Engelli bireylerin hem sosyoekonomik hem de kültürel temsilinden kaynaklanan eşitsizlikler sebebiyle çok yönlü dışlayıcı süreçlere maruz kaldığı, yardım etkinliklerinin bu süreçleri daha da kötüleştiren önemli bir etken olduğu savlanmaktadır. Engellilik ve sosyal dışlanmada yardım etkinliklerinin rolünü kavrayabilmek için, ortopedik engelli bireylerle ve engellilikle ilgili çalışan STK’ların temsilcileriyle derinlemesine mülakatlar gerçekleştirilmesini de içeren nitel bir araştırma yapılmıştır. Ancak bu çalışma, doğası gereği heterojen olan engellilik deneyiminin tümünü yansıtmamakta ve yalnızca incelenen grubu temsil etmektedir. Bu çalışmada, engellilere yönelik yardım, sosyokültürel dışlanma ve engellilik arasındaki ilişkinin; sosyal baskının bireyselleştirilmesi, muhtaçlık ekseninde yardım anlayışıyla şekillenen sosyal politikalar, ayrımcı uygulamaları besleyen yasama çalışmaları, engelliliğin tıbbileştirilmesi, STK’ların rolü ve öncelikleri, engelliliğin kültürel temsili ve dinsel etmenler gibi birbiriyle etkileşen karmaşık yapısal ve kültürel faktörleri içerdiği belirlenmiştir. Ayrıca, sadece STK’ların değil devletin engellilik hakkındaki anlayışının da ağırlıklı olarak yardım ekseninde şekillendiği gözlemlenmiştir. Bu araştırmanın en önemli sonuçlarından biri, yardım etkinliklerinin kişileri engelli olan ve olmayan biçiminde iki dışlayıcı gruba ayırmak yoluyla yarattığı düalizm sonucu engelli bireylerin yaşadığı sosyokültürel dışlanmaya etki ettiğidir.

Anahtar Kelimeler: Engellilik, Sosyal Dışlanma, Yardım, Engellilere Yönelik Sosyal Baskının Bireyselleştirilmesi, Engelli STK'ları

To My Mother Seyhan Girişmen

For encouraging me to take the leading role in my own life

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LIST OF ABBREVIATIONS

AKP	Justice and Development Party
By-Law	The By- Law on Criterion and Classification of Disability and Medical Reports Issued to People with Disabilities
DPI	Disabled People's International
ICF	The International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ILO	International Labor Organization
IŞKUR	Turkish Employment Agency
NGOs	Non Governmental Organizations
ÖZİDA	Administration for Disabled People (now re-established as General Directorate of Disabled and Old Aged Services under the Ministry of Family and Social Polices)
UN	United Nations
UNDESA	United Nations Department of Economic and Social Affairs
UNDP	United Nations Development Programme
UPIAS	Union of the Physically Impaired against Segregation
UN CRPD	UN Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
MFSP	The Ministry of Family and Social Polices
TURKSTAT	Turkish Statistical Institute
SUT	Communiqué on Healthcare Implementation

CHAPTER 1

INTRODUCTION

Throughout the world, 10% of the population is considered disabled which makes more than 600 million people living with some sort of disability and out of which, 400 million reside in developing countries (WHO &World Bank, 2011). As there is a higher risk of disability at older ages and with the increasing trend of ageing populations all over the world, disability and disability related concerns are getting more and more important.

A similar picture is also valid for Turkey where disabled people constitute 12.29% in the overall population. In spite of representing such a high proportion in the population, disability studies and analysis of disability related policies are quite new in Turkey. Therefore this thesis aims to contribute to a relatively new area of study by analyzing social exclusion experiences of disabled people and the role of charity[1] in the exclusionary processes.

Disability is a multidimensional phenomenon and a widely debated concept by many social scientists from diverse disciplines. It is directly related with and affected by the interaction of a different set of factors such as health conditions, personal and environmental factors (WHO &World Bank, 2011). The complexity of disability not only reveals itself in its conceptualization but also the way disabled people experience disability.

Disability has its real meaning and experience in political economy, social and cultural contexts through interaction with other people. Therefore, both the political

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[1] In this thesis, charity refers to the charitable giving of NGOs as well as social assistance given by state institutions bearing the traces of strong charitable dominance. For further explanations please see methodology section.

economy and the social transformations have reflections and profound effect on how disability is experienced. Long before being considered as either a medical or a socio-political construct, disability was associated with the anger of God and considered as a charitable obligation. Hence, each period has revealed its conceptualization of disability having roots in the economic mechanisms and the social transformations.

To better understand the theoretical and practical relationship between social exclusion experiences of disabled people and the role of charity, it is crucial to analyze the medical as well as the social model of disability and how diverse disability conceptualizations determine the significance of charity in the lives of disabled people. Because as in the words of Oliver (2004, p.19) “disability models are ways of translating ideas into practice”.

The medical model of disability pathologizes disability and underlines incapability that focuses solely on the impaired body unable to perform like “normal people”. According to the medical model, disability equals physical limitation and impairment. Whereas the social model of disability which is emerged as a response to a long lasting neglect of social forces in terms of disability, challenge the idea of “personal tragedy” and presented disability as a social construct. The disabling effect of society and social structures become the major focus and the attention is shifted from the individual to the society.

Another turning point in terms of disability conceptualization occurred after the 80’s economic and social transformations. The economic restructuring influenced by neoliberal policies had also its reflection on the conceptual and practical world of disability (Soldatic and Meekosha, 2012). Again there has been a shift from social to individual emphasis, as the public programs have given greater emphasis on individual pathology notion and a citizenship conception stressing domestic responsibilities and charitable giving (Rioux &Valentine, 2006).

As Jean François Ravaud and Henri Stiker (2001) contend, from ancient times until today, people with disabilities have experienced different forms and degrees of social exclusion depending on the time, context and society they live in. Each epoch has developed its exclusionary processes and responses to tackle social exclusion.

Within the context of disability, charity with its controversial nature has always been a critical player in relation to economic-structural and social-cultural exclusion. Its role with regard to disability experience is widely debated. Once been a sole source of income for disabled people, charity also became a pretext for their removal from the social community or a ground to mobilize disabled people. With its income related aspects such as motivation to address material deprivation as well as non-income related features such as humanitarian motive, religious duties and cultural influence, charity provides significant information on how disability is experienced.

While this study aims to shed light on the relationship between disability and charity, it also intends to provide insight into multi dimensional forms of social exclusionary experiences. Studying charity targeting disabled people in the Turkish context is believed to reflect how society integrates disability into social and cultural knowledge and how the set of different structural and cultural factors interact with each other in determining disability experience.

This thesis aims to explore the role of charity in relation to social exclusion experiences of disabled people as well as the structural and cultural factors behind charitable efforts targeting disabled people in Turkey. In order to elaborate the complex relationship between disability and charity and provide insight into multi dimensional forms of social exclusionary experiences, this study consists of five chapters.

In the second chapter, the methodology of this study is presented. Information about the aim of the study, operational definitions as well as the overview of research sample and data collection is provided. The field experiences also give clues about the disability experience in Turkey; therefore together with constraints of the study, field experiences are mentioned in the second chapter to guide further studies.

In the third chapter, the conceptual framework regarding social exclusion, disability and charity is presented. Firstly, social exclusion is conceptualized with reference to different approaches and debates. Diverse responses in tackling social exclusion are also elaborated. Second part of theoretical framework conceptualizes disability and history behind this process. The relationship between social exclusion, disability and charity is also set out by referring to diverse exclusionary dimensions as well as reasons behind this complex relationship. Structural and cultural factors behind the significance of charity in disability are discussed as well.

The fourth chapter, through the interviews conducted with disability NGOs and people with orthopedic disabilities sheds light on the inner dynamics of charity, disability and social exclusion relationship in the Turkish context. The structural and cultural factors determining the significance of charity dominance in disability and the role of charity in social exclusion are discussed in detail by taking age and gender variables into account. The influence of charity activities on the creation of disability culture and exclusionary processes are presented likewise.

The fifth chapter consists of a brief summary concluding the major findings of this study as well as social policy discussions and suggestions for action at the national level.

CHAPTER 2

RESEARCH METHODOLOGY

2.1 The Aim of the Study and Research Problem

Disability studies and analysis of disability related policies and strategies are quite new in Turkey. In line with being a new area of interest, there is a shortcoming concerning available statistical data and information, which makes it difficult to identify actual situation of people with disabilities.

In Turkey most comprehensive and recent statistical data related with people with disabilities dates back to 2002. According to the Turkey Disability Survey (2002) conducted by TURKSTAT in cooperation with the Administration for Disabled People (ÖZİDA), 12.29% of the overall population is disabled. Analyzing and tackling problems such as social exclusion experiences of such a big population of people is vital not only for this specific group of people but also for society as a whole.

Since the disability experience is directly related with and affected by the interaction of a different set of factors such as health conditions (ex: diverse impairments), personal (ex: gender, age, ethnicity, income level, socioeconomic status etc.) and environmental factors (WHO &World Bank, 2011), considering disabled population as a homogenous group of people is misleading and far from capturing its complexity.

Despite the conventional approaches that overly emphasize and associate some disability groups' experiences as the universal truth, this study acknowledges the heterogeneity even within the same disability group and avoids misleading generalizations. To reveal the complex interactions that disability bears, this research's sample is constrained with people with orthopedic disabilities who are the most significant subjects of charity activities in Turkey and who correspond to a great number of people with 1.25% in the overall population.

As discussed in the following chapters, social exclusion experienced by people with disabilities has a multidimensional character with intertwined social, cultural and economic dimensions that cannot be considered independent from each other. Deprivation in one dimension has evident impact on other dimensions and may result in a vicious cycle of exclusionary processes. Consequently, isolated and single focus policies unable to identify and challenge multidimensional subordination are far from addressing complex processes experienced by disabled people. Therefore the dynamics of social exclusion of people with disabilities requires more attention.

In Turkey although there are some studies examining social exclusion experiences of people with disabilities, there are not any studies examining the dynamic relationship between social exclusion and charity as well as its effects on construction of disability concept and diverse dimensions of exclusionary processes. Moreover, exploring cultural and social understandings of disability and their relations with the structural context can mirror complexity of subordination as well as policies and regulatory practices leading to such subordination. Consequently the main aim of this thesis is to focus on the interaction between charity and social exclusion experience as well as set of drivers behind this interaction from people with orthopedic disabilities' perspective. It is believed that analysis at personal level not only sheds light on individual experience but also provides valuable insights regarding cultural, structural and social forces.

Charity has always been part of the picture related with disabled people and it has always been a powerful source in the creation of disability culture. It is hypothesized that charity activities in Turkey exacerbate disabling barriers and oppression experienced by disabled people. As Shakespeare (2000, p.55) voices "charity becomes a necessity in the context of an unequal and disabling society". With the effect of neoliberal era, the limited role and restricted engagement of the state exacerbated already existing inequalities. "The rise of neoliberal ideas has led to an increase in policies and programs that view disablement as primarily an individual pathology" (Rioux & Valentine, 2006, p.56). The shift of attention from social to individual led to privatizing disadvantages. Consequently neoliberal understanding which is the trending approach in the world as well as in Turkey, urged individuals to become more active social agents regarding their risks and NGOs to become more active with their activities in advocating and assisting disadvantaged groups.

In line with this trend, there is a greater emphasis on individualism, responsibilities as well as charitable giving to tackle inequalities. There is a relationship between the rise of neoliberal polices and increasing importance of charities within the context of disability. Instead of social rights and entitlements arising from citizenship that requires social state understanding, there has been a shift towards temporary, individualized and populist aids which reinforce clientalism. (Koray, 2005, Macit, 2010). The degree of visibility and charity's role in enhancing the feeling that "problems are solved" also make charity a desirable means and lead to gain great support from society.

In Turkey, charity for disabled people is among the most commonly supported activity by society and interest in these activities seems to maintain its importance in the near future. Despite its social acceptance and support, there is not a comprehensive research identifying cultural and structural factors behind charity in Turkey as well as its effect in the context of social exclusion experiences of disabled people. Also identifying underlying forces as structural and cultural systems creating subordination and unequal outcomes in diverse dimensions is crucial in order to establish appropriate and comprehensive policies.

Therefore this thesis aims to explore the role of charity in relation to social exclusion experiences of disabled people as well as structural and cultural factors behind charitable efforts for the sake of disabled people in Turkey. The question concerning "what sort of reflection do charity activities have on exclusionary patterns as well as on the meaning attributed to disability?" urges it necessary to evaluate charity, disability and social exclusion relationship.

This thesis investigates the answers to the following questions:

- How do the charity campaigns related with people with disabilities affect power relations in society as well as the dynamics of social exclusion experience in Turkey?
- What are the structural and cultural factors behind social exclusion of people with orthopedic disabilities through charity activities?
- Which parties, in what ways, when and how should be involved in the process of distributive justice?
- What sort of role do disability related NGOs have in charity processes?
- Do charity activities shift focus from society to individuals and individualize the social exclusion of disabled people?
- To what extent does charity serve as a useful tool in the context of disability? Does charity mechanisms harm more than it help?
- Can charity activities contribute to the political mobilization of disability rights movement in Turkey leading to a more organized and rights based movement?
- Do charity activities reinforce a perception of a homogeneous disability conceptualization and experience in Turkey?

2.2 Major Definitions

Throughout the thesis couple of concepts is frequently used and needs further explanation to avoid conceptual confusion.

Disability refers to the definition employed by the Convention on the Rights of Persons with Disabilities (CRPD), which Turkey is one of the signatory state parties. Thus, “disability is an evolving concept and that it results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (UN CRPD, 2006). Moreover in order to clarify, for the purpose of this thesis two terms as “people with disabilities” and “disabled people” are used interchangeably without any intention to overemphasize medical and biological aspects of disability.

Since **charity** is a broad concept, it is necessary to narrow down what covers charity. Within the scope of this thesis, charity involves diverse activities introduced and managed by disability related NGOs such as distribution of mobility and assistive devices as wheelchairs, battery operated wheelchairs, crutches, orthesis, prothesis etc and fund raising efforts for health operations for people with orthopedic disabilities. In other words, within the scope of this thesis, charity symbolizes a collective or individual action to remediate a "individual" need. However, fund raising activities as well as donations for scientific research for degenerative diseases are out of the scope of this study. Social assistance given by state institutions adopting need based distributive system and charitable understanding is also covered to understand complex relationships of charity.

Social exclusion will be used as a multi-faceted notion involving economic-structural exclusion with a distributional dimension and social-cultural exclusion covering social relations, values and norms with a relational dimension that result in unjust relations as well as prevention of certain groups or individuals' full and equal participation through interrelated multi-dimensional processes.

2.3 Research Methodology and Data Collection

The research of this thesis consists of two main parts where first part involves a literature review about social exclusion, disability and charity conceptualizations and second part includes a qualitative study employing semi structured in-depth interviews with people with orthopedic disabilities and disability related NGOs whose main target group is determined as people with orthopedic disabilities in Turkey.

In order to understand multiple perspectives and diverse experiences as well as to better analyze the exclusion experience of people with disabilities in a detailed manner and the effect of charity on this dynamic experience, qualitative research method is preferred. By employing in-depth interview technique through semi-structured interviews, both NGO representatives and disabled participants are encouraged to express their opinions, feelings, motivation, experiences and perspectives about charity and disability in their own words. Since exclusion can be found in dynamics of various relationships, real life experience of parties involved in charity process is the major focus of this thesis.

Firstly, as being a critical player in charity activities, seven NGOs all around Turkey mainly dealing with orthopedic disability are interviewed through semi structured in-depth interviews regarding their structure, priorities, scope, charity eligibility criteria, means of fundraising as well as their perspectives on disability and the state's disability policy. Five of the interviewed NGOs bear organization for public weal status. The common thread to all selected NGOs is their involvement and interest in addressing the problems of people with "orthopedic" disability and selecting them as their main target group. The detailed profile of the interviewed NGOs is provided in Annex A[2].

On behalf of the selected NGOs, one of the executive board members or a representative appointed by the executive board is interviewed. Experiences of NGOs and their relationship with the state, society and people with disabilities shed light on social infrastructure, institutional, structural and cultural drivers and values. Based on NGO interviews certain patterns, priorities and trends about charity activities in Turkey are identified.

Accordingly, the charity activities performed by disability NGOs in Turkey involve wide variety of campaigns ranging from collecting plastic bottle lids to combining environmental recycling campaigns with distribution of assistive devices; short message services (SMSs) campaigns, sportive activities as marathon runs to raise funds as well as telethons. From NGOs' perspective, charity activities for people with orthopedic disabilities mainly center on the distribution of mobility and assistive devices such as wheelchairs, battery operated wheelchairs, crutches, orthesis, prosthesis etc. as well as fundraising campaigns for disabled people's health operations. Moreover, it is identified that charity campaigns in Turkey mainly target people with orthopedic disabilities due to the significance of assistive equipments in the lives of people with orthopedic disabilities as well as the visibility and tangibility of charity activity outcomes. This tendency is also in line with the data provided in

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[2] Annex A: Profile of Interviewed Disability NGOs

2002 Disability Survey, which identifies people with orthopedic disabilities as one of the most important proportion of disabled population who use assistive equipments with a ratio of 19.65 %.

The priorities and eligibility criteria for charity set by selected NGOs also guided the selection of this study's sample. In view of the information provided by NGOs, "age, diverse income levels and gender" are considered as important elements in selecting a sample that ensures diversity and avoids overly homogeneous respondent profiles. However some of the interviewees were reluctant to specify their income level and did not want to express the exact amount of income they have. For that reason income level analysis of the respondents is categorized and analyzed in relation to the minimum wage in Turkey, which is at the same time a significant reference point in deciding who is eligible for governmental supports such as disability benefits.

Second part of the interviews involves semi structured in-depth interviews with 16 people with orthopedic disabilities who are asked to share their experiences and perspectives. During interviews, 95 questions[3] aiming to explore various aspects as demographic features, conceptualization of disability, effects of charity campaigns, representation of people with disabilities, role of disability related NGOs, disabled people's opinions about NGOs and the state policy as well as their expectations from society, NGOs and the state are asked to participants. The field research is carried in Ankara and disabled interviewees are selected through purposive snowball sampling method and reached through already interviewed participants by taking gender and age limitations into account.

The participants are selected as people with "orthopedic" disabilities above 18 years old living in Ankara. Since "gender" is an important feature creating additional adverse influence in disability experience and "age" being a critical concern in the level of activeness and eligibility for charity from NGO perspective, the sample is equally distributed between gender and age intervals of 18-40 and 40+.

As disabled people are able to retire earlier than usual retirement ages, for the purpose of this thesis, people with disabilities older than 40 years of age are assumed

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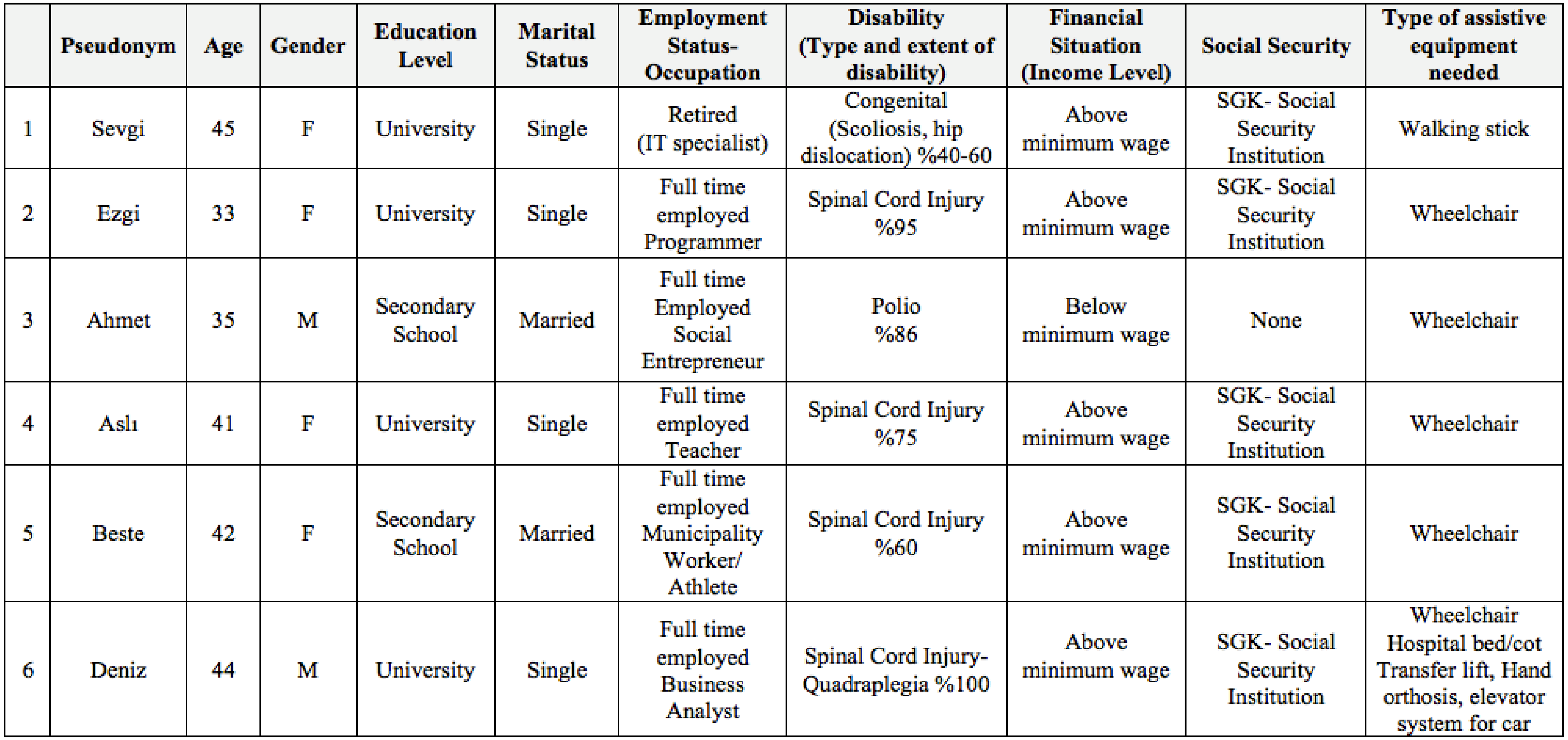
3 Annex C: Interview Questions

to be less active and more distant from work and social life due to early retirement opportunity. Moreover, in the literature review it has been identified that considering "older" disabled people as less productive and more distant from employment results in different social and institutional responses in relation to disability and makes them less attractive target focus for the state policies as well as institutional framework. "Older people with disabilities are rarely seen as disabled in quite the same way that younger or adult disabled are" (Priestley M, 2004 p.97) creates further concerns about exclusionary patterns they may face. In line with this assertion, the information provided by selected NGOs also confirms that age is an important criterion of eligibility for charity.

To examine the experiences of participants in a detailed manner, the research sample involves 8 women and 8 men equally distributed between 18-40 and +40 age intervals. Among these respondents, 4 males and 6 females are single whereas 6 of the respondents are married (4 males-2 females). The age of female interviewees ranges from 48 to 18 years old whereas the age of male interviewees' ranges from 50 to 24 years old. Except one of the respondents, all of them are under the social security system. In terms of the educational level, 9 of the respondents have a university degree (5 females-4 males), 5 of them are graduated from high school (4 males- 1 female) and 2 of them are graduated from secondary school (1 female-1 male).

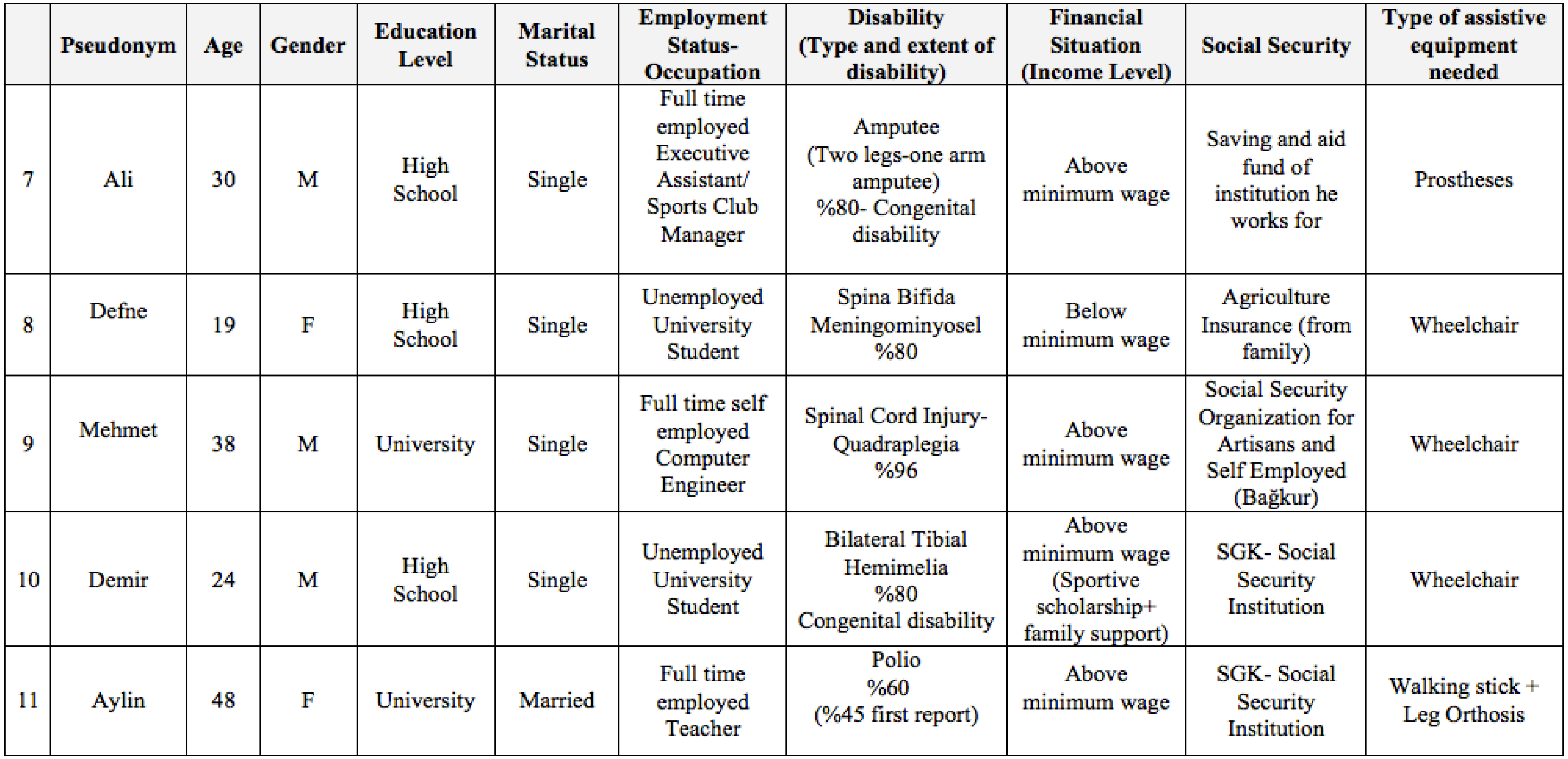
According to the Circular on Procedures and Principles regarding the Enhancement of Social Aid and Employment Relationship, the extent of disability between 40-69% is distinctively referred to signify employability of disabled people belonging to this range, which can be interpreted as a state level categorization of extents of disability implying less severity. With regard to the extent of disability characteristics, 10 respondents have a 70% or above extent of disability and 6 of them have an extent of disability between 40-69%. Except one, all of the respondents belonging to the 70% or above extent of disability group stated "wheelchair" as an indispensable need for their lives. The other types of assistive equipments needed are stated as prosthesis, orthesis, walking stick, transfer lifts etc. Table 1 provides the detailed information about the profile of interviewees.

Table 1. Socio-Demographic Information about Interviewees



	Pseudonym	Age	Gender	Education Level	Marital Status	Employment Status-Occupation	Disability (Type and extent of disability)	Financial Situation (Income Level)	Social Security	Type of assistive equipment needed
1	Sevgi	45	F	University	Single	Retired (IT specialist)	Congenital (Scoliosis, hip dislocation) %40-60	Above minimum wage	SGK- Social Security Institution	Walking stick
2	Ezgi	33	F	University	Single	Full time employed Programmer	Spinal Cord Injury %95	Above minimum wage	SGK- Social Security Institution	Wheelchair
3	Ahmet	35	M	Secondary School	Married	Full time Employed Social Entrepreneur	Polio %86	Below minimum wage	None	Wheelchair
4	Aslı	41	F	University	Single	Full time employed Teacher	Spinal Cord Injury %75	Above minimum wage	SGK- Social Security Institution	Wheelchair
5	Beste	42	F	Secondary School	Married	Full time employed Municipality Worker/ Athlete	Spinal Cord Injury %60	Above minimum wage	SGK- Social Security Institution	Wheelchair
6	Deniz	44	M	University	Single	Full time employed Business Analyst	Spinal Cord Injury- Quadraplegia %100	Above minimum wage	SGK- Social Security Institution	Wheelchair Hospital bed/cot Transfer lift, Hand orthosis, elevator system for car

Table 1. (continued)



	Pseudonym	Age	Gender	Education Level	Marital Status	Employment Status-Occupation	Disability (Type and extent of disability)	Financial Situation (Income Level)	Social Security	Type of assistive equipment needed
7	Ali	30	M	High School	Single	Full time employed Executive Assistant/ Sports Club Manager	Amputee (Two legs-one arm amputee) %80- Congenital disability	Above minimum wage	Saving and aid fund of institution he works for	Prostheses
8	Defne	19	F	High School	Single	Unemployed University Student	Spina Bifida Meningominyosel %80	Below minimum wage	Agriculture Insurance (from family)	Wheelchair
9	Mehmet	38	M	University	Single	Full time self employed Computer Engineer	Spinal Cord Injury-Quadraplegia %96	Above minimum wage	Social Security Organization for Artisans and Self Employed (Bağkur)	Wheelchair
10	Demir	24	M	High School	Single	Unemployed University Student	Bilateral Tibial Hemimelia %80 Congenital disability	Above minimum wage (Sportive scholarship+ family support)	SGK- Social Security Institution	Wheelchair
11	Aylin	48	F	University	Married	Full time employed Teacher	Polio %60 (%45 first report)	Above minimum wage	SGK- Social Security Institution	Walking stick + Leg Orthosis

Table 1. (continued)

	Pseudonym	Age	Gender	Education Level	Marital Status	Employment Status-Occupation	Disability (Type and extent of disability)	Financial Situation (Income Level)	Social Security	Type of assistive equipment needed
12	Beril	24	F	University	Single	Full time employed Trainer	Paraplegia %80	Above minimum wage	SGK- Social Security Institution	Wheelchair
13	Can	48	M	University	Married	Full time employed Teacher	Polio %47 (%60 according to first medical report)	Above minimum wage	SGK- Social Security Institution	Walking stick
14	Utku	41	M	High School	Married	Full time employed Worker	Polio %60	Above minimum wage	SGK- Social Security Institution	Walking stick + Leg Orthosis
15	Elif	26	F	University	Single	Full time employed Civil Servant	Paraplegia %80	Above minimum wage	SGK- Social Security Institution	Wheelchair
16	Selim	50	M	High School	Married	Retired Civil Servant / Active Trainer	Scoliosis %40	Above minimum wage	SGK- Social Security Institution	None

This study uses the power of personal experience to analyze the research problem of this thesis. The field research of this study is conducted between March of 2015 and February of 2016, due to the availability of the participants and my workload. Each interview lasted approximately 70 minutes. In order to test accuracy and understandability of questions, two pilot interviews are conducted as well. Most of the interviews are made face to face whereas in some cases depending on the preference of respondents, interviews via phone or online means are also conducted. The face-to-face interviews were made either at some public places as restaurants or cafes or at home of the participants.

Each interview is recorded by means of an audio recorder with the permission of interviewees and decoded afterwards. The verbatim transcriptions of each interview are analyzed carefully and grouped to reveal certain trends in structural and cultural contexts by keeping the research questions in mind.

In order to ensure confidentiality and respect privacy instead of citing real name of interviewees, pseudonyms are used. Additionally, at the beginning of each interview, participants are informed about the research and an engagement document[4] is signed to respect the privacy of respondents.

2.4 Constraints of the Study

As in any thesis, there are some limitations due to restricted resources and time schedule. In order to understand dynamic relationship between social exclusion and charity activities, interviews of seven known NGOs for public weal mainly dealing with orthopedic disability are conducted.

However, disability involves diverse and heterogeneous experiences. But within the scope of this thesis, it is not possible to cover every impairment type and reflect corresponding experience. Consequently, in order to narrow participant profile, specifically people with “orthopedic” disability are interviewed. There are 16

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[4] Annex B: Engagement Document

interviewed participants in total and the results of this study only represent the interviewed group.

At this point, it is important to state that due to participant profile restricted to orthopedic disability; this qualitatively carried research is not representative of entire disability experience that involves diversity. Therefore, the sample is not aimed to be representative. Further studies can analyze the effect of charity on social exclusion experience of different impairment types as well as diseases with progressive deterioration such as ALS being an important target group of charity fundraising events.

In addition, leaving charity campaigns related with degenerative diseases and scientific research for cure out of the scope of this thesis poses another constraint. In other studies, analyzing charity campaigns related with degenerative diseases as well as fund raising activities for medical research and its effect on social exclusion experience can be beneficial as well.

In the future studies, it will be also beneficial to involve the views of government officials, state bureaucrats and politicians in order to have a broader understanding of dynamic relationship between charity campaigns and social exclusion experience. For that reason, they can be considered in future studies.

Lastly, this study gives insight to disability and social exclusion experience in a developing country that is neglected for a long time in disability studies. Therefore, it is believed to contribute to disability studies from a developing country’s perspective.

2.5 Field Experiences

During field interviews, I had both positive and negative experiences related with my traits. As being the first Turkish female athlete who had a gold medal at Paralympic Games, I did not have any difficulty while convincing NGO representatives as well as respondents to make an interview for the purpose of this thesis. Except one of the potential participants’ confidentiality concern and refusal to take part in this research, all of the participants were willing to participate and express their experiences and opinions sincerely. Therefore, my sportive career as well as disability helped me a lot in accessing relevant parties to share their experience and opinions.

However, during some interviews as a disabled woman, I had difficulty to get detailed opinions of participants because they presuppose that I already know the situation that they are referring to. “You also know, you already experience the same problems” are the most common expressions I heard during interviews. For that reason I made more effort than I expected in order to understand the implicit messages that interviewees refer. Above-mentioned attitude can be also interpreted as; disabled people in Turkey believe in sharing homogeneous exclusionary experiences with regard to disability.

CHAPTER 3

CONCEPTUAL FRAMEWORK

3.1 Conceptualizing Social Exclusion

3.1.1 Conceptual Definitions and Characteristics of Social Exclusion

The concept of social exclusion is widely debated and yet defined in a variety of ways depending on the priorities that one takes into consideration. Throughout literature, it becomes obvious that there is neither a monolithic definition nor a single solution of social exclusion. Different discourses and ways of interpreting social exclusion lead to the emphasis of different causes and concerns as well as solutions. "The term social exclusion is so evocative, ambiguous, multidimensional and expansive that it can be defined in many different ways" (Silver, 1995, p.60).

In social exclusion literature, it is very common to trace the historical roots of social exclusion in French social policy, which dates back to the 60's. In France, it was used to refer to poor people in an ambiguous way during the 60's (Çakır, 2002). However, as referenced by most of the academic studies regarding exclusion, Rene Lenoir's definition of excluded in "Les Exclus" (1974) went beyond poor people and involved those unable to adjust to mainstream society and misfits which corresponds to one tenth of the French population at that time.

In the following years, with the increase in social problems such as rising unemployment, persistent poverty, weakened family ties, means tested assistance, increase in isolated individuals and rupture of social relations, social exclusion expanded its reference and more groups were included such as marginal and antisocial people, physically and mentally disabled people, school dropouts, abused children, immigrants, single parents and social misfits (Silver, 1995, Rawal 2008). With the rise in social problems, it becomes a key theme in current social policy debates. "The concept of social exclusion has evolved with the concept of social rights, rooted in the idea of the European welfare state" (UNDP, 2011, p.8). The influence of welfare state philosophy and its failure to address social problems was prominent in the expansion of social categories concerning social exclusion.

Once social exclusion concept became popular and widely used during the 90's, more emphasis was given to how to define it and how to evaluate influential factors as well as its indicators. After all this time from its first appearance, there still is no agreed definition of social exclusion. Instead, there is a variety of conceptualizations, which emphasize different aspects that will be analyzed throughout this chapter.

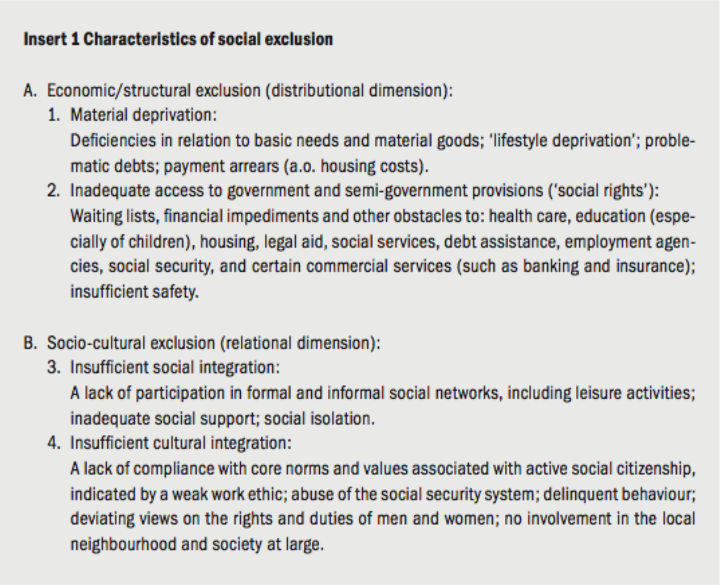
Paugnam (1996) contends that social exclusion is a reflection of becoming aware of society's dysfunctions and search for possible solutions. It is a way to assess performance and risks of a society in terms of social solidarity and individuals' well-being. Because of socio economic changes of the 70's such as emergence of new risks in labor market, breakdown of traditional communities and of social bonds as well as political and structural changes redefining citizenship, a shift in perspective becomes necessary. Consequently, the emergence of social exclusion concept due to above stated contextual changes at a time of welfare state crisis, emphasizes a dynamic instead of a static and a multidimensional rather than a one dimensional focus, and requires a distributional as much as a relational focus.

From a French perspective, being excluded refers to being outside of the social contract and generating potential threat to it. How to interpret exclusion involves contract-based approach with reciprocal responsibilities (Daly, 2006). The relationship between individuals and the community is important regarding exclusion in French tradition. Xiberras (1993) emphasizes the social relationships dimension by stating that individuals and the society have impact on the process. Defining social exclusion according to social relationships demonstrates a close relationship between social exclusion and social solidarity. He refers exclusion as a progressive breakdown of the social bonds attaching individuals to society (Xiberras, 1993, cited in Silver, 1995)

According to Bhalla and Lapeyre (1997), the social exclusion concept overlaps with poverty in a broad definition; however, it goes beyond poverty by underlining the relational as well as distributional aspects of poverty. Social exclusion has a wider focus on political, cultural and social dimensions rather than just signifying a financial deprivation. It is also a reflection of relationships between the state and individuals as well as the society and individuals. “A social exclusion framework is primarily an analytical framework for understanding society and deprivation, with context dependence as a central point of departure” (De Haan, 1999, p.17). However, social exclusion emphasizes whether a distributional aspect or a relational approach is another feature widely discussed in literature.

Within the context of above mentioned discussion, Room (1995) argues that social exclusion primarily addresses relational issues such as the absence of social ties, discrimination, participation, and mutual obligations; whereas, poverty primarily focuses on distributional issues as lack of resources. However, many discussions center on the intertwined nature of exclusionary processes making it impossible to separate distributional and relational dimensions from each other. (Bhalla and Lapeyre, 1997, Saraceno, 2000, Fraser, 1995).

Jehoel-Gijsbers and Vrooman (2007) in their study, to explain social exclusion differentiate between economic/structural exclusion with distributional dimension from socio-cultural exclusion with relational dimension and schematize the features of social exclusion as follows:



Insert 1 Characteristics of social exclusion

A. Economic/structural exclusion (distributional dimension):
  1. Material deprivation:
     Deficiencies in relation to basic needs and material goods; ‘lifestyle deprivation’; problematic debts; payment arrears (a.o. housing costs).
  2. Inadequate access to government and semi-government provisions (‘social rights’):
     Waiting lists, financial impediments and other obstacles to: health care, education (especially of children), housing, legal aid, social services, debt assistance, employment agencies, social security, and certain commercial services (such as banking and insurance); insufficient safety.

B. Socio-cultural exclusion (relational dimension):
  3. Insufficient social integration:
     A lack of participation in formal and informal social networks, including leisure activities; inadequate social support; social isolation.
  4. Insufficient cultural integration:
     A lack of compliance with core norms and values associated with active social citizenship, indicated by a weak work ethic; abuse of the social security system; delinquent behaviour; deviating views on the rights and duties of men and women; no involvement in the local neighbourhood and society at large.

Figure 1. Characteristics of social exclusion

Source: Jehoel-Gijsbers, G. & Vrooman C. (2007, p.17)

Accordingly, if one side of the coin is economic-structural exclusion, the other side of the coin is socio-cultural exclusion that involves insufficient social and cultural integration due to lack of participation in formal and informal social networks, social isolation and lack of compliance with core norms and values. Hence together with structural factors, social settings and cultural values and norms are equally important in social exclusion.

Appleton-Dyer and Field (2014) while discussing social exclusion, group different forms of exclusion under four key forms. According to them, each form of exclusion is intertwined and reinforces other dimensions. In their analysis, basically political exclusion refer to what extent certain groups are able to enjoy equal opportunities arising from political and human rights, economic exclusion signify lack of access to labor markets, access to material resources whereas cultural and social exclusion involve reduced opportunity in accessing education, social participation etc. as well as diverse values and norms leading to acceptance or rejection.

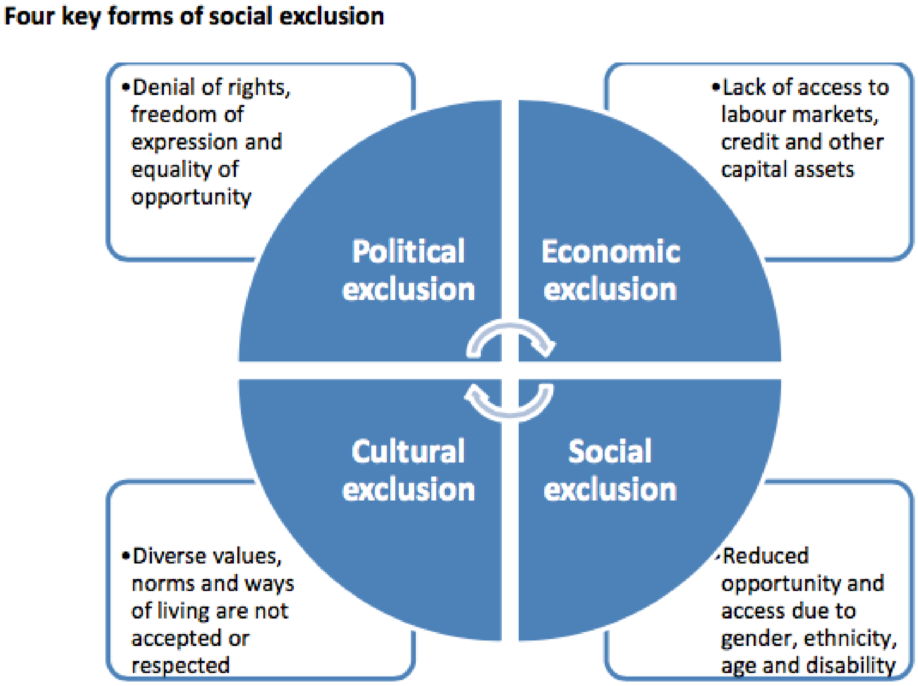


Figure 2. Key forms of social exclusion

Source: Appleton-Dyer and Field (2014, p.4)

While examining the concept of social exclusion Atkinson and Hills (1998) bring three elements to the fore. They emphasize crucial features as relativity, agency and dynamics in social exclusion. By underlining relativity, they argue that a reference to a specific time and place is needed and considering exclusion is meaningless unless an assessment of circumstances that includes socio-historical context is provided.

The importance of agency is another important feature in social exclusion. Not only individual or household level analysis is enough but also taking communal resources, institutions and systems, social infrastructure and social network into consideration is important. An individual may be excluded due to his/her decisions or due to the existing power structure over which he/she has no control at all. Lastly, the dynamism aspect is underlined by Atkinson and Hills (1998). Social exclusion is not a static condition referenced at a certain point. Instead, it occurs when individuals have little prospects for future and rather than focusing on current outcomes it emphasizes the processes through which people become excluded.

In the report of UNDP “Beyond Transition towards Inclusive Societies”, social exclusion is explained both as a process and as an outcome. “It is a process that pushes certain individuals to the margins of society and prevents their full participation in relevant social, economic, cultural, and political processes. As an outcome, it denotes the status and characteristics of the excluded individual” (UNDP, 2011, P.8). Understanding exclusion both as an outcome and as a process underlines the dynamic relationship of interconnected dimensions reinforcing each other such as lack of opportunity to acquire basic competencies, access to social life, health care, social relations, educational opportunities, employment status, and poverty.

Describing exclusion in relation to freedom is another perspective provided by Amartya Sen. He distinguishes between active exclusion that depends on legal restrictions or intentional policy for desired outcome and passive exclusion that is not intentional and emerges as a result of a complex institutional and social process. Unemployment experienced by migrants due to legal restrictions reveals an active exclusion whereas complex institutional factors or social processes without intention of employment specific decisions leading to unemployment are passive exclusion. Whether it is an active or a passive exclusion; Amartya Sen argues that any form of exclusion results in reduced human capabilities. Deprivations and reduced capabilities in one dimension affect and reinforce capabilities of other dimensions, which result in capability failures, and social exclusion has an instrumental function in this process (Sen, 2000). He associates social exclusion to capability perspective on poverty.

Within the context of social exclusion experienced by people with disabilities who are among the most deprived and neglected population as in the words of Amartya Sen, analyzing the reflections of fairness, justice and actual experience is important to shed light on complexity of exclusion process. “A theory of justice that confines attention to earning handicap only can hardly come to grips with the demands of fairness that are central to the foundations of justice” (Sen, A. 2004, p.5).

Sen distinguishes between “earning handicap” and “conversion handicap” where income is not the only determinant factor in the real experience of people with disabilities. Although it is more difficult to find a job, earn the same level of wage for the same job and retain it as compared to non-disabled peers, this is just one aspect of the difficulty they face and it is a means to an end. Converting the income earned into a good living or into desired states of being also appears as another important problem. According to Sen, with the same level of income due to medical and other disability-related expenses, it is not possible for a person with disability to have the same level of good living as compared to a non-disabled person. In addition to income related restrictions, social arrangements such as access to education or lack of qualified teachers for specific disability groups also limit inputs of good living. Thus, conversion handicap involves income related aspects, converting social competences to opportunities and negative social attitudes as well. As a result, people with disabilities may experience deprivations concerning capabilities. Therefore together with disadvantages faced in other dimensions, converting money and social facilities into actual experience of good living becomes a crucial problem.

Although there is no agreed definition of social exclusion, the emphasis on processes creating exclusion is one of its most underlined and commonly referred aspects. Ruhi Saith (2001) argues that concerns related with welfare state led to the emergence of social exclusion concept. Consequently, the starting point is closely related with institutions and the role of these institutions in the process leading to disadvantages and existing social inequalities. The emphasis is on disadvantaged situation that developed over time by multidimensional and cumulative effects. “The central definition of the notion of social exclusion stresses the processes through which people are being deprived, taking the debate beyond descriptions of merely the situation in which people are” (De Haan, 1999, p.5).

“If poverty is a photograph, social exclusion is a film” (Estivill, J. 2003, p.21) serves well as a metaphor to refer the complexity of exclusion. Instead of providing a snapshot, exclusion reveals interconnected relations both as a cause and an outcome.

> “Social exclusion may therefore be understood as an accumulation of confluent processes with successive ruptures arising from the heart of the economy, politics and society, which gradually distances and places persons, groups, communities and territories in a position of inferiority in relation to centers of power, resources and prevailing values”.

An alternative perspective to explore social exclusion set out by Chiara Saraceno (2000) is to recognize at least two different approaches, which point poverty and material deprivation on the one hand, and social disintegration and marginality on the other hand. The main focus is either on social conditions that affect individuals to be included or excluded from relevant resources and rights or the focus is on processes leading to individual or group belonging or detachment.

It is also possible to discuss the concept of social exclusion macro-sociologically or micro-sociologically. Distinguishing macro and micro causes and identifying exclusion from "above" or "below" is another perspective in conceptualizing exclusion. Top-down perspectives mainly consider exclusion as a result of an employment crisis or ineffective integrative social institutions or inadequate immigration policies; whereas, grass-roots perspectives with a bottom to top communitarian approach view exclusion as a crisis of community solidarity. All those analyses contribute to the discussion of social exclusion and show how flexible the concept of exclusion is. (Weinberg&Ruano-Borbalan, 1993, as cited in Silver, 1995)

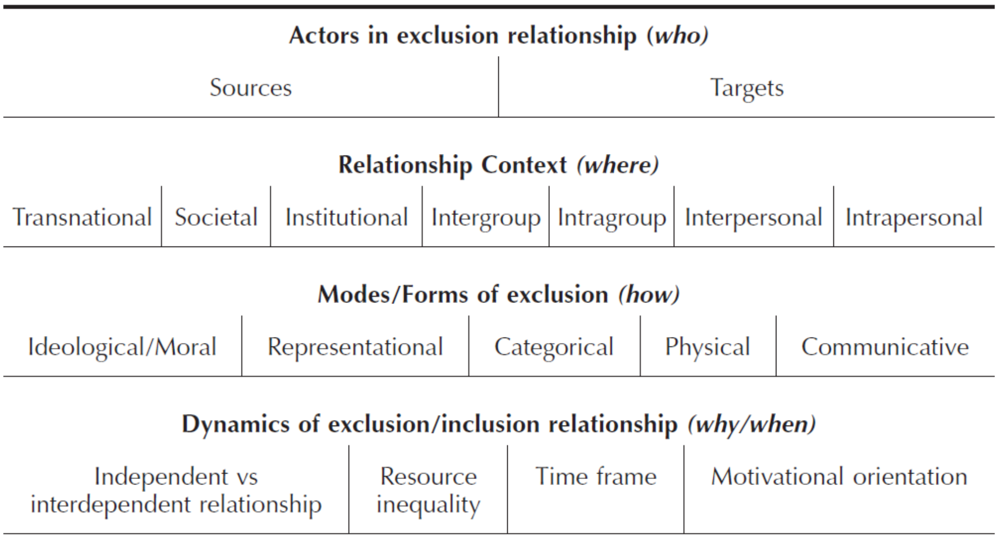
It is clear that social exclusion have different meanings for different people. Depending on diverse living conditions and socio-economic status, people consider different indicators as the basis of social exclusion and who to refer as socially excluded changes among groups. Ruhi Saith (2001) by referring to the ILO study states that majority of unemployed individuals define exclusion as unemployment and as lack of income; whereas, working women identify exclusion with literacy, illness, perversion and disability. On the other hand, according to housewives, employment is a key determinant in integration (Bedoui and Gouia, 1995 cited in Saith, 2001). Tania Burchardt (1999, in Morris 2001) conducts similar analysis where young disabled people are asked to define social exclusion and they refer;

> “not being listened to, having no friends, finding it difficult to do the kinds of things that non-disabled young people their age do, such as shopping, going to the cinema, clubbing, etc., being made to feel they have no contribution to make, that they are a burden, feeling unsafe, being harassed and bullied; and not having control over spending money, not having enough money” as the indicators of social exclusion (Burchardt, T.1999 cited in Morris 2001, p.164).

While some discussions regarding social exclusion emphasize the relational characteristic, the others point to its complexity, multi-dimensional nature, dynamic, connected, process oriented and cumulative features.

In line with these discussions, an alternative way to analyze social exclusion is introduced by Abrams, Hogg and Marques (2005, cited in Abrams & Christian, 2007) and involves identifying four elements such as the actors, the structural level of the exclusion relationship, the forms and modes of exclusion, together with the dynamics of exclusion. Within the context of this framework, if one aspect is missing in the evaluation, it means to obscure and restrict the way exclusion process is handled. All these elements relate to the questions of “who, where, how, why and when” exclusion happens. According to Abrams, Hogg and Marques, since causes and solutions to exclusion can be found in dynamics of various relationships, such a relational dynamic framework that involves relationship context, modes of exclusion and dynamics of exclusion is necessary to map and set out an adequate policy intervention.

Table 2. A relational dynamics framework for analyzing social inclusion and exclusion



Actors in exclusion relationship ***(who)***	
Sources	Targets

Relationship Context ***(where)***						
Transnational	Societal	Institutional	Intergroup	Intragroup	Interpersonal	Intrapersonal

Modes/Forms of exclusion ***(how)***				
Ideological/Moral	Representational	Categorical	Physical	Communicative

Dynamics of exclusion/inclusion relationship ***(why/when)***			
Independent vs interdependent relationship	Resource inequality	Time frame	Motivational orientation

Source: Abrams, D. & Christian J.(2007, P.215)

Burchardt et al. (1999) offer a different perspective through emphasizing "participation" element in defining social exclusion. Accordingly their social exclusion definition (1999, p.231) underlined participation in the normal activities of citizens in a given society whom they are geographically resident. In 2002, Burchardt et al. (p.30) reviewed their definition of social exclusion with an emphasis on its relative nature by underlining the importance of time and place and changed the wording form "normal activities" to "key activities". The key activities are classified under four dimensions and operationalized as:

- Consumption being measured by the capacity to buy goods and services and by savings.
- Production being measured by participation in economically or socially valued activities such as paid work, education etc.
- Political engagement being measured by involvement in local or national decision-making.
- Social being measured by regularity and frequency of meeting with family, friends and neighbors.

In the social exclusion literature, a common approach to define exclusion is to give a reference to employment status. Exclusion is commonly linked to a state of being excluded from paid employment in a legitimate economy and involves reduced entitlement within social security as an alternative support from the welfare system (Sapey, 2004). The emphasis on paid employment both as a reference and a key source of integration is widely used in the EU discourse on exclusion as well.

Levitas also underlines the importance of labor market integration and argues today's policy framework contrasts social exclusion with integration rather than social inclusion, which implicitly means integration into the labor market. To address exclusion through overemphasizing employment is not only feasible, but also inadequate because of focusing only on ability and productive skills and omitting valuing non-productive roles (Sapey, 2004).

In conclusion, there is not an easy and simple way to define social exclusion. The concept of social exclusion is both considered as an opportunity with its flexible nature enabling discussions and as a cliché repeating already existing and identified problems with a new conceptual name. However, it is certainly a multi-faceted notion that refers to both individuals and societies with a social relationship dimension, process of social disqualification, accumulation of disadvantages, interrelated multi-dimensional process and dysfunctions of the system as well as power relations with both distributional and relational dimensions.

3.1.2 Debates on Social Exclusion

As being one of the most debated concepts, social exclusion offers a variety of criticism and discussions as well. One of the most commonly agreed criticisms about social exclusion is the reductionism in its explanation through dividing society into two overly homogeneous divisions as included/ins and excluded/outs (Silver, 1995, Jackson 1999, in Rawal 2008, Levitas, 2005)

With a simple reduction that positions exclusion right opposite of integration, the idea concerning "who to be included, into what, under which conditions or at the expense of what" is barely addressed. Without challenging already existing economic, social, institutional and political structures, considering inclusion as including the "excluded ones" in the wonderful world of the "included" is somewhat very problematic and criticized by many academic studies. (Levitas 2005, Silver 1994, Rawal 2008, Grech, 2009).

Related with the above-mentioned discussion, John Viet-Wilson (1998) distinguishes between strong and weak versions of social exclusion discourse; where, weak social exclusion discourse seeks the solution via transforming excluding characteristics of excluded people and makes them integrated into a dominant society. Therefore, in the case of disability, this approach does not challenge underlying ableist assumptions at all. It only aims to reintegrate those not conforming to the understanding of the “normal”. Whereas, strong social exclusion discourse aims to question power structures by addressing the role of parties effective in the exclusion process and aims to address exclusion by restructuring and reducing the powers of exclusion (Viet-Wilson, J. 1998, cited in Saloojee, A. 2003). In other words, the strong social exclusion discourse aims to address the underlying relations, structure or parties creating the end point/status of exclusion. Such an approach would expect to result in a more accurate and permanent solution to the process of exclusion.

Oversimplifying the groups as included and excluded limits detailed analysis of the exclusion process and obscures specific experiences as well as power relations, which result in a limited perspective. As argued by Jackson (1999) “dualistic opposition between inclusion and exclusion tends to emphasize exclusion as the opposite of integration, which limits exploration of the contradictions in the multiplicity of exclusion or the paradoxes of simultaneous inclusion and exclusion.” (Jackson, 1999 cited in Rawal 2008, p.169). Moreover, instead of a dispersed, contingent and unstable notion of power, the social exclusion concept assumes a unitary form of power accepting the “included” as being powerful and the “excluded” as powerless (Rawal, 2008). As a result, the disconnected policy initiatives that are unable to identify unjust power relations by placing these groups in a single category or recognize actual experiences of individuals either neglect the multi-dimensional approach or obscure the reality faced by these groups and result in estranged policies from social, economic and political contexts.

Lack of clarity and theorization are other issues emphasized in the debates regarding social exclusion. It is seen as an ambiguous label to redefine already existing concepts as poverty under a new term. (Benington and Geddes, 2001 in Rawal 2008, Estivill, 2003, Kilmurray, 1995 cited in Şahin 2009). On the other hand, there are others such as Littlewood et al (1999) and Silver (1994) who see the fruitful discussions and diverse definitions depending on different contexts as an opportunity as well.

3.1.3 Different Responses to Tackle Social Exclusion

Because of the multi-dimensional character of social exclusion and its context specific nature, it is not possible to fight against the consequences as well as the whole process with a single strategy. However, “policies were frequently based on the policy makers’ analyses which did not fully take into account the real situation on the ground” (UNDESA, 2009, p.19).

The transformation taken place during the 70’s and the 80’s had a strong influence on how to perceive and conceptualize social exclusion and design responses accordingly. Adverse economic and social environment of the late 1970s and 1980s together with structural adjustment programs resulted in a major shift in social policies with an emphasis on more targeted policies aiming vulnerable and “deserving” marginalized groups. As a result, instead of addressing underlying structural barriers with a rights based approach together with a holistic vision, how to simply target those needy, vulnerable groups or individuals became a major concern. However, whether those targeted policies led to an effective response regarding the existing excluded status or process of exclusion of the marginalized individuals remained a critical question.

> “Addressing social exclusion does not relate only to targeted programs and cash transfers, as there were other strategies that needed to be considered such as enhancing coordination among multiple service providers, fostering household and community participation and addressing cultural beliefs and attitudes” (UNDESA, 2009, p.20).

Redistributive policies involving a categorical approach that aims to identify deserving ones are the most commonly referred policies to tackle the exclusion process as well as its consequences concerning people with disabilities. The strong relation between economically disadvantaged position and exclusion provide an important incentive to address the reallocation of resources in order to ameliorate the situation of the excluded ones. However, due to the increasing effect of structural adjustment programs and the burden created by social transfers on the budget together with challenges arising from globalization and global competition, a "stricter" categorical approach regarding social entitlements is promoted instead of a universalist approach. Concomitantly, the voices critiquing "dependency culture" effect of those entitlements are being heard more and more.

Ruth Levitas (2005) argues that the connection between poverty and exclusion experienced by vulnerable groups such as people with disabilities initially emphasized the significance of "redistributive policy" discourse; however, the recent paradigm shift with neoliberal policies emphasizing individuality over collective responsibility offer "employment" as a panacea for social exclusion and attracts more attention to individual deficiencies. Such a shift in identification of problems at individual level presents employment as a magical solution to exclusion and enhances the questioning of individually based deficiencies while obscuring broader structural barriers creating a disadvantaged position. Therefore, a lack of analysis involving political economy of exclusion draws the attention on perceiving social exclusion as a failure of integration into the labor market. This tendency is closely related with "the centrality of work within neoliberal workfare." (Soldatic and Meekosha, 2012, p.204).

Similar to Levitas' argument, Ferge (1997) also contends that there has been a paradigm shift at the end of the 20th century in terms of social policy and elaborates that "old paradigm concerns with collective responsibility for social reproduction and efforts to reduce inequalities; whereas, the new paradigm operates upon an individualized notion of responsibility" (Ferge 2007 cited in Yates, S. & Roulstone, A. 2013, p.458). Therefore, it can be argued that conceptualizing exclusion problems in individual rather than structural terms becomes a commonly encountered approach with the emergence of neoliberal policies (Yates, S. & Roulstone, A. 2013, Rioux & Valentine, 2006). Such preference affects the emphasis given to individual centered approach supported with a clientalist orientation that negatively affects recognition-oriented problems of excluded groups as well as overemphasizing strict categorical redistributive policies. Consequently, recognition-oriented policies become second-class policies not attracting much attention in the policy agenda.

Likewise, Yates and Roulstone voice the effects of individualized focus in the context of disability and argue,

> "The heterogeneous forms of impairment and unpredictable complexities in the forms of disablement facing disabled young people are thus seen to be poorly addressed by an individualized focus that shifts attention away from considerations of broader structural inequalities and disablement." (Yates and Roulstone 2013, p.464).

Consequently, an emphasis on individuality and a belief that individuals bear responsibility for their own situation together with simplistic social capital enhancement does not address the big picture of complex exclusion process. Such an analysis is also supported by Fraser (2000) who differentiates affirmative remedies from transformative ones in response to exclusion. According to Fraser, both affirmative remedies aiming to address unequal outcomes without touching deep structures generating disadvantages and transformative remedies addressing structural processes creating inequality are different means to address exclusion. However, the most important distinction between these remedies is that while affirmative ones reinforce existing group differences, transformative ones question constructed dichotomies and try to destabilize them. In a way, affirmation and transformation offer contradictory means against subordination.

Herein it is beneficial to recall Fraser's (1995) argument that injustice is directly related with political and economic structures affecting socio economic inequality such as exploitation, economic marginalization and deprivation as well as related with cultural representation rooted in communication, symbols, representation, and discourse. Her analysis identifying different sources of injustices requires diverse forms of strategies valuing "redistribution" and "recognition" efforts to achieve justice.

However, in reality drawing a clear line that differentiates economic injustices from cultural ones is not possible because both of them are interconnected and reinforce each other. Moreover as Fraser (1995) introduces most of the social groups are "bivalent collectivities" that face hybrid forms of injustices and exclusion that require redistributive as well as recognition efforts together.

> "Bivalent collectivities, in sum, may suffer both socioeconomic maldistribution and cultural misrecognition in forms where neither of these injustices is an indirect effect of the each other, but where both are primary and co-original. In that case neither redistributive remedies nor recognition remedies alone will suffice. Bivalent collectivities need both" (Fraser, 1995, p.78).

In line with Fraser's conceptualization, it will not be wrong to argue that disabled people can be considered as bivalent collectivities due to socio economic injustices as well as cultural representational inequalities they frequently face as a social group. Hence, ameliorating and addressing actual experiences of disabled people require more than a "one size fits for all" approach. Both redistribution and recognition remedies are equally important, interconnected and necessary.

Most of the time, to address political and economic problems associated with disability affirmative redistributive remedies in the forms of disability allowances or common governmental policies employing a social integrationist discourse (Levitas, 2005) that emphasize employment policies, as quotas or sheltered workplaces are believed to solve inequalities efficiently. Such surface reallocations, while providing material aid enhance socially constructed group differentials and strongly differentiate "normal people" from "deserving, needy disabled". They do not challenge complex structures producing disadvantages. Instead disabled people are expected to prove eligibility either through strict means tests or via a medical evaluation that stresses the privatization of the situation.

"The privatization of the disadvantage justifies and perhaps even mandates a restrictive or passive engagement in its resolution" (Rioux & Valentine, 2006, p.51). Consequently, affirmative remedy that aims to correct inequalities at first, itself contributes to stigmatization and exclusion through promotion of difference. Eventually the recipients of affirmative distributive remedies may end up experiencing misrecognition as side effects. A vicious cycle of economic and cultural subordination becomes an end result.

In addition to affirmative redistributive efforts, affirmative cultural remedies also inadequately address the complexity of exclusion process. Efforts to revalue bivalent collectivities (Fraser, 1995) as disabled people within existing structures without identifying the root causes of misrecognition inevitably miss the links between cultural and economic injustices. These incomplete efforts overlook institutional and complex connections. According to Fraser (2000) designing policies to address misrecognition or “politics of recognition” should not mean to abstract links between economic inequality and recognition problems. Otherwise, it may end up being an identity politics or it may end up degrading distributive injustices as a secondary effect of misrecognition. As a result, it may displace politics of redistribution, which is not its aim in the first instance.

Fraser (2007) distinguishes among different strategies to tackle exclusion. Based upon her analysis, if exclusion is economically rooted, strategy should be transformative redistribution aiming to change political economy structures, if it is culturally rooted, transformative recognition strategy linking both misrecognition and maldistribution is crucial and if it is of politically rooted exclusion, it should be addressed via transformative representation or combination of these strategies. Being aware of the complex connections is of vital importance to address the social exclusion experiences of “bivalent collectivities” (Fraser, 1995).

Designing responses and policies to combat social exclusion of people with disabilities requires a very complex and comprehensive approach as well as being aware of the connection between recognition and distribution dilemma. Richard Sennett (2003) who examined the issue of “respect” in relation to welfare draws attention on two concepts as “self reliance and respect”. In an era emphasizing individuality, he raises concern on the fact that gaining respect is associated with being self-reliant. Therefore, in a more individualistic world, individuals are expected to be self-reliant in order to gain respect. (Sennett, 2003 cited in Sapey 2004). People with disabilities who need assistance eventually experience problems of respect, which will definitely affect recognition and consequently, their exclusion.

3.2 Conceptualizing Disability

Disability is a multidimensional phenomenon, widely debated concept by many social scientists from diverse disciplines. Despite being a major research topic associated with the medical area for a long period of time, psychology, sociology, social policy and social services etc. have also been crucial parts of disability research. Each discipline offers different perspectives to frame disability leading to diverse evaluation and consequently different policy formulations.

As well as social exclusion of people with disabilities is directly related with how disability is constructed and interpreted, disability in its concept is strikingly reflective in exploring social exclusion of the disadvantaged.

Throughout the world, 10 % of the population is considered disabled which makes more than 600 million people living with some sort of disability and out of which, 400 million reside in developing countries (WHO &World Bank, 2011). Therefore, people with disabilities compose a huge percentage of the world population requiring a comprehensive analysis of their experience in order to evaluate and offer adequate policies.

“Ways of viewing disability, of developing research questions, of interpreting research results, of justifying research methodology and of putting policies and programs in place are as much about ideology as they are about fact” (Rioux, 1997 p.101). Therefore, it is important to argue that political economy and social transformations have reflections and profound effect on how to conceptualize disability and design policies accordingly. In line with this argument it will be beneficial to set a framework for evaluation and evolution of disability models from early periods until today.

3.2.1 History Behind Disability

Many academicians consider the history of disability as “history of otherness” or “history of silence” during which changing social, economic and political perspectives together with medicalization emphasis on disability contributed to the construction of the “other” as well as repression and marginalization of people with disabilities as a social group. Religious, medical, modernist, materialist and post-structuralist perspectives have important impact on how to conceptualize disability and set a framework for disability models. Thus, how the difference is understood is a key factor on how to respond to people with disabilities. These diverse perspectives have also influenced how societal attitudes and perceptions changed over time and offer different definitions and approaches to disability.

Braddock and Parish (2001), in their article “an Institutional History of Disability” analyzed people with disabilities from ancient times until recently. Long before considering “disability” as either a medical or a socio-political construct, they stated that in ancient Greece and Rome people with disabilities were seen as evil spirits and they were born with disabilities due to the wrath and displeasure of Gods. In most of the cases, children born with deformities or impairment were abandoned or killed. This era associating physical differences and disability with anger of God and resulting in infanticide was referred as the primitive era by Jansman and French (1994 cited in McPherson et al, 2003). In addition to abandonment and infanticide, the Romans abused people with disabilities in entertainment and circuses as well (Woodill & Velche, 1995).

From early periods until recently, bodily difference played an important role in social structures by labeling certain bodies as norm and some others varying or deviating from this norm as “others”. While in Ancient Roma and Greece bodies deviating from the norm were abandoned or exposed to infanticide, in our day, there are other forms of discriminative practices affecting the lives of the disabled people.

Similar to antiquity, in Middle Ages, when rule of Divine God was unquestionable, disability was associated with sin, immorality and witchcraft due to having demonological and supernatural origins, which resulted in various forms of punishment and even persecution of the people with disabilities. However, also during the medieval period, by being considered as poor beggars, it was possible for disabled people to receive aids and alms from rich people (Braddock and Parish, 2001, Woodill & Velche, 1995). In line with this paradoxical treatment in the medieval period regarding disability, the religious perspective regardless of reference to a specific religion considers people with disabilities both as charitable objects and punishment from God due to sin or displeasure.

Despite a domination of paradoxical treatment about disability both as a punishment and a charitable obligation, during the 16th century, there were other practices as well. Miles (2000, cited in Braddock & Parish, 2001) stated that there were educative initiation for people with hearing impairment where employed ones in Ottoman courts trained the other hearing impaired about the signing system and let them be part of the society to some extent. The loss of hearing function was considered as a useful qualification to secure confidentiality in a very privileged and risky environment as Ottoman courts. However, as Miles argues during that time in Western Europe, it was very rare to consider educating people with hearing impairment and expecting their contribution to society.

Unlike some exceptional practices as stated above, the oldest known disability model is the *religious model of disability* which involves considering people with disabilities as charitable objects in need of assistance. Furthermore, disability is also considered as a reflection of immorality and sin, which brings shame, and labeling of the “other” (Clapton & Fitzgerald 1997, Arıkan 2002).

The emergence of enlightenment thinking, questioning presupposed essential relations between human beings, nature and God, brought science and scientific approach to the fore. Scientific knowledge is believed to improve the lives of human beings. Such a profound shift emphasizing scientific knowledge and reason had serious effect on how to conceptualize, diagnose and classify disability. People with disabilities became objects of investigation and control of science and consequently undesirable ones are segregated in institutions. The dominance of science in understanding disability influenced medical view that treats individuals with impairment as objects of study and resulted in increasing involvement of doctors and scientific experts regarding disability. (Woodill & Velche 1995, Clapton & Fitzgerald 1997, Braddock and Parish 2001).

Additionally scientific dominance revealed itself in eugenic movement as well and severely affected disabled people. The idea of controlling inherited qualities to create a master race and improving races by eliminating undesirable, poor genes resulted in massive massacre of people with disabilities. The most well known eugenics movement was experienced during Hitler Germany where disabled people were executed because of their biological inferiority and bodily or mental imperfections. The belief that "solution to cultural problems would come through better human breeding" (Biklen & Mlinarcik, 1978 cited in Kliewer C. & Drake, S. 1998, p.99) resulted in medical control, segregation, sterilization and ultimately elimination of useless and bad human genes that are considered as bearing unnecessary social cost (Kliewer C. & Drake, S. 1998).

The progress of enlightenment led to the dominance of science more and more in exploring and colonizing the body and mind of the people labeled as "different". In disability literature, it is widely stated that the role and decision making capacity of professions controlling the body and mind became more important, instrumental and powerful. This resulted in medical dominance in conceptualizing disability, which is usually referred as *medical model of disability*.

Moreover, as contended by Çağrı Doğan (2008) in his article "Disabled People of Post Modern Capitalism", enlightenment thinking used machinery of capitalism as a base and developed the idea of a never failing body under the control of the mind/reason and considered the impaired body as a malfunctioning machine in need of repair. Consequently, the ones unable to be repaired like "people with impaired bodies" are regarded as wreckage machinery. Since their value in terms of work was unprofitable, they were regarded as useless and incapable. People with disabilities are treated as non-standard workers with higher liability and less productivity (Russell M, 2001). Such understating influenced profoundly the way disability is understood and interpreted.

Although prior to the 18th century, conditions were also difficult when production mainly depended on agriculture and crafts trading, people knowing each other and having a relatively fixed place were considered as easing features. However, industrial revolution and the capitalist system are argued to be the turning point in the lives of people with disabilities. Deborah Stone (1984) contends "the disability concept was essential to the development of an exploitable workforce in early capitalism and remains indispensable as an instrument of the state in controlling the labor supply" (Stone, 1984, p.179). Emergence of capitalism with new market forces, difficulty of working in newly emerged industries as mining and machinery dominant production systems that require "healthy, strong, efficient" bodies influenced the degree of medical involvement in interpreting disability (Finkelstein, 1981).

The materialist perspective underlines role of capitalist system and transition from agrarian to industrial society tearing social fabric as important exclusionary factors in the lives of disabled people. "Production for profit undermined the position of physically impaired people within the family and the community" (Finkelstein V., 1981, p.60). Those were the times when productive activity had great value and those not working were seen as responsible for their own poverty, and a distinction was made between "unwilling ones" who were able but not working and "unable ones" as impaired people. (Soldatic&Meekosha, 2012). The latter was considered eligible for charity due to their impairment, which was associated with inability. As Stone (1984 p.118) argues "the purpose of the disability category is to keep everyone in the work-based distributive system except for the very neediest people, those who have legitimate reason for receiving social aid". Thus disability became a restrictive mechanism as well as an administrative category through which people are categorized according to either a distributive system based on work or a distributive system based on need.

With such consideration, Finkelstein argues that cripples were transformed into disabled people. They were entitled to charity at the expense of removal from social community. Davis (2000 cited in Braddock and Parish 2001, p.12) also supports this view by arguing, "disability was not constituted as a social category prior to the 18th century, even though impairments were no doubt quite prevalent in the general population".

With the transition from feudalism to capitalism, emergence of new working environments together with harsh working conditions due to new production processes had impact on institutionalization. Family members became less available to assist and care about their disabled relatives. The institutionalization appeared as a solution to provide necessary care and assistance by hospitals and medical professionals. However, at the same time, the institutionalization process yields to the segregation of the disabled people (Oliver, 1990). The idea that people with disabilities had to be protected through institutions by getting them out of society's sight restricted their economic activity and made them dependent on charity as a sole source of income (Finkelstein, 1981, Oliver, 1990, Soldatic and Meekosha, 2012). This process that excludes people with disabilities from almost all spheres of life is identified as "hegemony of care" by Vic Finkelstein.

According to the materialist perspective on disability, economic mechanisms generated disability as a social category and it was necessary and instrumental to separate deserving ones from undeserving individuals in this process. In other words, industrial capitalism socially created an individualized approach to disability. Martha Russell (2001, p.92) also supports this view by stating, "disability became an important boundary category through which persons were allocated to either work-based or needs-based system of distribution".

Based on the Marxian political economy perspective, prejudicial attitudes are regarded less effective on disability oppression as compared to the capitalist mode of production (Russell M, 2001). However, this argument is very criticized later on by many disability researchers such as Tom Shakespeare, Nicholas Watson, Mairian Corker who emphasize the effect of culture, representation, discourse and meaning on prejudicial attitudes.

Oliver (2004, p.19) argues that "models are ways of translating ideas into practice" and the medical model of disability takes its roots from biological deficiency, deviance and points "personal tragedy". For that reason, the *medical model of disability* pathologizes disability and emphasizes incapability as well as "biological inferiority" that focuses on the impaired body unable to perform like machines or like "normal" and "fit" people. One of the most prominent discourses that underline uselessness of disabled people fed by medical model's implicit message is the expression of "it is better to be dead than be disabled". Usually disability is defined as a loss or it is associated with incompleteness. As a result, it is commonly believed that disability either requires an individual effort to overcome the situation or should be addressed via charity and pity.

According to the medical model, disability equals physical limitation and impairment. It is associated with illness and a "medical label" that needs to be cured as well. According to Shakespeare (2006), the medical model of disability is similar to a medically oriented racial discrimination. Since, this model depoliticizes disability by abstracting it from the social, economic and political contexts, a feeling of self-blaming and being at fault of disabled people is promoted.

> "Medical model is rooted in biology and it serves the interests of the medical profession and those professions and other economic and political groups allied to it. It is an intellectually and politically limited model for responding to the problems covered by the term `disability' in the modern world" (Williams G, 1996, p.208).

The medical model of disability with its sole focus on individual pathology or deviance made a paradigm shift necessary in understanding disability by taking the disabling effect of social context into account. Therefore, it can be argued that the *social model of disability* emerged as a response to a long lasting neglect of social forces in terms of disability. This model with a disability standpoint not only challenged an absolute non-disabled human kind and performative evaluation based on non-disabled people, but also questioned the medical discourse. The social model is labeled as a milestone and became a strong reference almost in all articles and researches about disability.

"Since the 1960s there have been various attempts to provide and develop a conceptual schema to describe and explain the complex relationships between illness, impairment, disability and handicap" (Oliver, 1996, p.30). The mid 70's witnessed a profound shift in understanding disability with the initiation of UPIAS (Union of the Physically Impaired against Segregation) founded by Paul Hunt and Vic Finkelstein. Further on, Mike Oliver developed the idea of UPIAS and introduced a new perspective called the "*social model of disability*" (Thomas C, 2004). In contrast to the medical model conceptualization, it is not the impairment that disables people, but it is the role of society and social structures that disable people with impairments. For that reason, the most important feature of the social model is its precise differentiation between impairment and disability. This differentiation is formulated by Disabled People's International (DPI) as follows:

> "Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Oliver, 1996, P.31)

By rejecting the personal tragedy model, it shifts attention from the individual to the society. Disabling social, political and physical barriers, attitudes, prejudices, institutionalized discrimination together with inaccessible environment ignoring the existence, needs and potential of people with impairments become the major focus. Disability is regarded as a social construct. Since the major cause of disability is seen as social structures instead of an impaired body or limited functions of people, it aims to address the structures restricting people with disabilities and prevent them achieving their potential (Oliver, 1990, Thomas, 2004).

According to the social model, impairment is important at personal level. It can even be considered as a tragedy at individual level, but the most important aspect is seen as societal restrictions that disabled people experience and these restrictions are even called as "crime" by Finkelstein (2001). In other words, impairment belongs to the private sphere; whereas, disability is a matter of social, economic and political sphere. Hence, the social model offers a sharp distinction between biological and societal features.

During the time period it emerged, it was necessary to distance from biological reference or impairment because biological difference is considered as "inferiority" and it is seen as the major cause of disability. In order to attract attention to the socially inferior situation of disabled people, institutionalized discrimination and social structures such as the attempt to distance impairment from disability can be considered as a means to create a stronger argument and "a practical tool for challenging disablism" (Oliver, 2004). However, although it has been widely accepted, the success of the social model of disability is not without any criticism.

Although the social model is a turning point regarding disability, its conceptualization leaving impairment to personal sphere with a strong dualistic and binary approach is widely criticized as well. The dichotomy between impairment and disability as well as social model's inefficiency in addressing the complex interaction between impairment and disability in the daily experiences of people with disabilities are criticized to a large extent. Carol Thomas, in her article "How is disability understood? An examination of sociological approaches", states that both post structuralists such as Shakespeare, Watson, Crocker together with sociologists of chronic illnesses and medical sociologists such as Bury and Williams criticized the social model due to its denial regarding realities of impairment on disability. In line with the above-mentioned criticism Gareth Williams argues that

> "Focusing too much on the impairments is seen to deflect attention from the systematic way in which the environment excludes people from participation in civil society. Placing too much emphasis on the politics of exclusion may be regarded as a way of underplaying the real effects of different impairments and the complex, `negotiated' aspects of everyday life, thereby creating a spurious homogeneity" (Williams, 1996, p.195).

Shakespeare (2013) also criticizes the way social model neutralizes the effect of impairment and states that even if all social and attitudinal barriers are eliminated, there will still be disadvantages and limitations arising because of impairments. He contends that neutralizing or downplaying the effect of impairment is just a "Pollyannaish optimism". The question he raises that "if impairment is something so neutral why would everyone try to avoid it" appears as a challenging criticism to neglect real and material nature of the impairment in the social model.

However it can be argued that the social model did not ignore the effect of impairment; instead, it highlighted the less recognized aspects as "social construction" and "social restriction" imposed on disabled people because until that time, the major determinant concerning the exclusion experience of the disabled people was always seen as impairment and biological deficit. Hence, the aim is not to underestimate the realities of impairment, but to show and underline the less obvious, ignored structural side and consequences of exclusion and in return motivate disabled people as a political movement. In order to highlight long time forgotten underlying causes, the social model formulated its discourse and words so that personal impairment effect is voiced less and disability is expressed as an outcome of multiple and complex structures involving social, political and economic contexts.

The clear distinction between impairment and disability is defined as problematic because representations of impairment are also socially and culturally determined. For that reason, reducing impairment just to a biological state makes the big picture of disability incomplete and problematic. Besides, those who criticize social model argue that both disability and impairment are different aspects of a single experience; therefore, it is not logical to separate one from the other with a clear line. Moreover a pluralist and open debate that value and voice differences among disabled people and recognizing heterogeneity is as important as stressing collective action as well as shared similarities and shared oppression (Shakespeare, 2006). For that reason instead of being stuck in a disability and impairment dichotomy, a debate open to consider gender, class position, diversity of impairment and respective experience is believed to contribute more to the richness of disability conceptualization.

The other criticism to the social model involves the denial of causal relationship between impairment and disability, normalizing tendency, ignorance of personal experience and its overly homogenizing nature. However, Mike Oliver, the father of the social model of disability, responds to these critics by underlining the social model’s pragmatic nature instead of being a social theory and importance of collective action in addressing disability oppression as well as emphasizing social barriers rather than personal limitations (Oliver, 1996). Emphasis on collective action and the social model’s contribution to this collectivity is important because Oliver further asserts that classification and segregation based on impairment together with the failure of single impairment organizations to address oppression made it necessary to break the link between impairment and disability. Therefore, he suggests introducing a social model of "impairment” instead of modifying the existing social model, which had profound effect on transforming the self-consciousness of disabled people. He also sets an analogy between a hammer and the social model as practical tools and if used properly instead of being stuck by criticizing, they are tools for social and political change (Oliver, 2004).

In disability literature, it is common to differentiate individual based approaches to disability from structural ones. Although named differently by different academicians, disability models stem from either individual or structural origins or a combination of both. Marcia H. Rioux (1997) identifies four social and scientific formulations related with disability reflected in the treatment of persons with disability in law, in policy, in research agendas and in programs. In her analysis, bio-medical (medical approach) and functional approaches (rehabilitation approach) take origins from considering disability as an individual pathology; whereas, environmental and rights-outcome approaches focus on social pathology. However, as in the words of Rioux (1997), these formulations are not mutually exclusive nor present a chronological order and none of them is inherently wrong.

Another turning point in terms of disability conceptualization occurred after the 80's economic and social transformations. The economic restructuring influenced by neoliberal policies had also its reflection on the conceptual and practical world of disability. Questioning of the state's efficacy leading to minimum state as well as post-modern critique on one objective truth through science and essentialist perspectives, challenged homogeneity of groups and required a revision regarding unit of analysis which also affected how disability is conceptualized. Decline of class-based politics together with blurring of boundaries and questioning of unifying theories creating wholes (Beckett, 2006, p.739) bring cultural issues, and structural reforms to the fore on the agenda of movements. Consequently, whether "it is possible to construct a grand theory of disablement that is valid and pertinent for all impairment groups across all cultural settings" (Lang 2001 cited in Grech 2009, p.775) becomes a critical question in disability conceptualization.

With the effect of the post modernist shift, class based politics lost its importance and fragmented identities are emphasized more. However, as argued by Shakespeare (1996, p.106) "class is a particularly powerful determinant of the disability experience". It has direct effect on the consequences and the degree of exposure to oppressive relations. To some extent, due to obscured presence of class in social movements, Shakespeare argues that in disability movement there is a dominance of middle class experience which is not able to properly emphasize poverty and exclusionary patterns.

Instead of adopting grand narratives of homogeneity and labeling social barriers as sole enemy, discourses taking different factors such as race, ethnicity, gender, and sexual orientation into account are emphasized in shaping experiences of disadvantaged groups. Although rejecting disability as a personal tragedy is a common point between the human rights model and the social model, disability is seen as an outcome of multiple forces and not just a consequence of social barriers. Moreover, Davis (2006, p.233) argues that "with post-modernist shift, the disability movement quite rightly desired to include disability as part of the multicultural quilt. If all the identities were under the same tent, then disability wanted to be part of the academic and cultural solidarity that being of a particular, oppressed minority represented". This significant shift moved attention from the economic structures and related ideologies creating disablement to the effect of discourse, culture and language concerning disability (Barnes, 2012). The link between disability and human rights and importance of law in the context of disability are highlighted more and more.

In line with the above mentioned developments, the dominant discourse of this period with a strong emphasis on identity underlines disability as a human rights issue.

> "In this period with the rise of neoliberal understanding, the serious deterioration related with rights and intellectual breakdown are tried to be replaced by human rights approach. However human rights approach emphasizes negative rights and does not stress social and economic rights equally. Social and economic equality request gained by social model approach is ignored and there is a shift from social to individual emphasis" (Okur & Erdugan, 2010, p.247).

Marcia Rioux and Fraser Valentine (2006) also support the above stated analysis and argue that there is again a shift in unit of analysis as most of the public programs give greater emphasis on individual pathology notion and a citizenship conception stressing domestic responsibilities and charitable giving. "Old charitable mechanisms and systems, together with national and local poor laws, which denied beneficiaries certain civil rights in exchange for assistance, were refashioned and adapted to market forces" (Estivill, 2003, p.6). As long as equality and rights based approach do not create further burden or spending on government as entitlements, people with disabilities can exercise and enjoy equal citizenship arising from human rights. However, when rights based approach appears as a threat to economic rationale, it is not possible to see rights based reflection on disability policies. Therefore, confusion regarding law and policies in understanding disablement as well as various disabling barriers and its connection to equality appear as critical aspects in need of answer in the context of human rights approach to disability.

Human rights emphasis is also shared by multi lateral agencies as UN and emphasis on equality, freedom, empowerment, non-discrimination as well as variation in human characteristics as richness and as diverse potential contributions appeared as prominent features. According to Okur and Erdugan (2010), the rights-based discourse to disability that is dominant after the 80's is either called by some still the social model or the social model with an appearance of human rights perspective or directly called the human rights model of disability by others. Regardless of the name or title, disabled people are emphasized as rights' holder and the main highlight is on the systematic processes able or unable to accommodate differences as disability. "Human rights approach to disability insists that governments take measures to foster inclusive societies that anticipate and respond to variations in human characteristics that are inherent to the human condition" (Rioux&Cabert, 2003, p.11). Therefore, efforts promoting equal participation opportunity on par with others and equality of opportunity are among crucial aspects in the context of human rights approach.

The human rights approach to disability is referenced by many as a magical invention to voice disability oppression. However, despite its major aim of emancipation and being dominant discourse of present day, the human rights approach to disability is also criticized because of its insufficiency to deconstruct disability and alter the disadvantaged position experienced by the people with disabilities. Besides, it is also judged to be lagging behind in terms of stressing social rights as equally as the social model on the rationale of neoliberal polices stressing dependency and burden on the state.

At this point, the concept of "conversion handicap" introduced by Amartya Sen is helpful to assess the human rights approach to disability. Converting equal opportunities and equality regarding rights do not guarantee equal outcomes and choices as well as equality in terms of pursuing one's potential. Therefore, it is also necessary to establish supporting mechanisms ensuring equality both at income and outcome level. However, because of restrictions based on the economic rationale of this epoch, it seems a bit unrealistic to establish supporting social, economic, cultural and political mechanisms to achieve practical reflections of equality. This leads to "confusion and tension in framing the legal and social parameters of what human rights and equality mean for people with disabilities" (Rioux&Valentine, 2006, p.66). Despite being a strong appeal concerning the "rights" perspective, in terms of creating effective outcomes, the human rights approach to disability does not perform well. Consequently, equality over equity with an emphasis on equality of opportunity instead of ensuring equality of outcomes becomes the prominent discourse (Okur & Erdugan, 2010, Clapton & Fitzgerald 1997).

In a brief sense, although the history of disability involves different disability conceptualizations, it can be summarized that during the pre-capitalist era, the traditional-religious model was dominant; whereas, with capitalism, medicalization of disability occurred and lately after the 80's, a fragmented analysis becomes a dominant one. Moreover, despite of being named differently by different academicians, disability models either stem from individualistic medical origins or structural or a combination of both origins. Lastly, as can be clearly understood from this section's discussion, disability cannot be conceptualized without referencing to the historical context and economic, political as well as social structures and practices of respective epoch. Above-mentioned historical process of disability conceptualization had its reflections on how to define and perceive as well as how to respond to disability.

3.2.2 Different Conceptualizations of Disability

In line with the above-mentioned discussions about disability conceptualizations, there have been various attempts to define disability as well. Depending on the priorities taken into consideration and the point of departure that one takes either by employing social or medical or fragmented perspectives, different definitions of disability are introduced. Therefore, there is not a monolithic definition of disability, and each perspective and organization such as the UN or different disability organizations offer their own definitions emphasizing different elements. Consequently, due to conceptual ambiguity and terminological confusion, defining disability is very hard and controversial.

Davis (2006, p.232) underlines the differentiation between impairment and disability by stating “impairment is the physical fact of lacking an arm or a leg but disability is the social process that turns impairment into a negative by creating barriers to access”; whereas, Michael Bury, who contributed to International Classification of Impairment Disability and Handicap (ICIDH) defines disability as a “lack of ability to perform an activity in a normal manner” with a strong medical emphasis (Thomas, 2004, p.575).

Defining disability is at the same time closely related with politics; as a matter of fact, it is politics by its nature (Oliver, 1996). How to define disability is important not only to determine who will be eligible for the state benefits or who will be exempt from citizenship responsibilities, but also to specify policy target groups and to define who law cannot discriminate against. Moreover, definitions and the language have direct impact on the lives of people with disabilities. As in the words of Foucault (1981 cited in Grech 2009, p.773), “words not only communicate, but conjure up images that shape a reality of separations, of superiority and inferiority and of hierarchy”. Definitions or the way a concept is defined reflect power relations as well. At this point, it is important to refer to Oliver (1996), who attracts attention to defining disability process during which disabled people are systematically excluded and not consulted, which resulted in attempts to introduce their own disability definition involving socio-political perspective.

After a long lasting neglect of disabled people’s perspective and suggestions on how to define disability, in 1976, the Union of the Physically Impaired against Segregation (UPIAS) introduced a socio-political definition of disability as follows:

“Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society”. This was very crucial because it challenged the idea or assumption that impairment is the sole and major determinant of disability.

With the disability activism after the mid 70’s, there has been increasing interest in disability issues at international level as well. This interest had its reflection on

World Health Organization’s (WHO) efforts to formulate a definition of disability in 1980 that resulted in the International Classification of Impairment Disability and Handicap (ICDH). In defining disability, ICDH uses a three-fold approach differentiating impairment, disability and handicap with a strong medical reference not taking disabled people’s perspective into account (Barnes, 2012). According to ICDH formulation,

> “Impairment is any loss or abnormality of psychological, physiological or anatomical structure or function. Whereas disability means any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. Finally handicap signifies a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role (depending on age, sex, social and cultural factors) for that individual” (WHO, 1980 cited in Barnes 2012, p.18).

ICDH is widely criticized because of its emphasis on normality, medicalization and reference to impairment as cause of disability affecting people with disabilities to be perceived as incapable and in need of cure. Therefore, ICDH’S disability definition is found misleading by many disability organizations.

Further attempts to address critics and define disability by referring to its multidimensional, complex, relative and dynamic nature involve the International Classification of Functioning, Disability and Health (ICF) introduced by WHO in 2002. The prominent change in this definition is to highlight “interaction” among different factors, involvement of people with disabilities and emphasis on environmental factors. To introduce a balanced approach considering medical and social parameters, disability is defined as:

> “An umbrella term referring to a dynamic interaction between health conditions and contextual factors as personal (age, gender, social status, and life experiences) and environmental (physical, social, and attitudinal environment for example, products and technology, the natural environment, support and relationships, attitudes, services, systems, and policies.)” (WHO &World Bank, 2011, p.4).

ICF’s definition of disability has three interrelated areas that involve *impairment* (ex: spinal cord injury, visual impairment), *activity limitations* (ex: not being able to walk or hear) and *participation restrictions* such as discrimination and inaccessibility (WHO & World Bank, 2011). Although criticized for not adequately addressing power relations in the social context (Barnes, 2003), ICF’S new definition established a conceptual frame for the bio-psycho-social model incorporating medical, social aspects and their interaction that also influenced disability definition's of UN Convention on the Rights of Persons with Disabilities (CRPD). According to CRPD, which Turkey is one of the signatory state parties:

> "Disability is an evolving concept and that it results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. 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 CRPD, 2006).

There have been a variety of definitions adopted in different countries throughout the development of disability policies. "The meaning of disability varies and depends on the hybrid socio-cultural contexts in which it is placed" (Grech, 2009, p.772). While defining disability, some countries emphasize the medical approach, stressing impairment-based definitions, while some others prefer definitions based on the social model differentiating impairment and disability and stressing on disabling society, and some others adopt definitions deriving from the bio-psycho-social model.

In Turkey, until recently, there have been some medical aspects incorporated to the definition of disability in the Law on Disabled People adopted on 01.07.2005.

> "Disabled is the person who has difficulties in adapting to the social life and in meeting daily needs due to the loss of physical, mental, psychological, sensory and social capabilities at various levels by birth or by any reason thereafter and who therefore need protection, care, rehabilitation, consultancy and support services."

However, the Law on Disabled People was recently amended and had important changes both in terms of the use of language and how disability is understood and conceptualized with a strong social reference. According to the Law on Disabled People amended on 06.02.2014,

> "A person with disability is an individual with physical, mental, intellectual or sensory impairment at various degrees influenced by environmental and attitudinal factors that hinders their full and effective participation in society on an equal basis with others".

Definitions are important to shape real life experiences, but although above stated definition involves a significant progress regarding disability understanding, it is up to governments to complement legislative efforts with their policies and strategies to make people with disabilities as equal members of the society or to ignore them.

3.3 Social Exclusion and Disability

Throughout the world, people with disabilities are among the most vulnerable groups experiencing exclusion and affected by the consequences as well as process of social exclusion. Almost exclusively every academician studying social exclusion mentions people with disabilities as a marginalized group subject to social exclusion (Silver H, 1995, Rawal 2008, Sen 2004, Appleton-Dyer and Field, 2014). “Certain people are systematically devalued and excluded from particular domains simply because they are members of a specific social category or group” (Hutchison P. et al, 2007, p.36). Esping- Andersen (1999) also stresses the similarity between casts and socially excluded groups with predetermined socially defined roles, limited access to both resources and services, lack of future prospect and inherited unemployment etc. Therefore, exploring social exclusion in a comprehensive framework through examining the status and processes experienced by people with disabilities not only stresses income related aspects, but also non-income related oppression.

From ancient times until today, people with disabilities experience different forms and degrees of social exclusion depending on the time, context and society they live in. “In Middle ages, some disabling conditions such as deafness, epilepsy, and mental disabilities are believed to have demonological origins and such understanding led to conceive them as witches which resulted in their persecution” (Braddock, D. & Parish, S. 2001, p.20); whereas, with enlightenment, people with disabilities became objects of investigation and control of science and segregated in institutions. Moreover, in religious documents it is also common to refer them as either punishment from God or charitable obligation that society needs to address. Eugenics movement, deriving from the idea of controlling inherited qualities, is another severe form of exclusion that people with disabilities experienced in the history of disability. “At the end of the 19th century, eugenics era gained momentum with the belief in superiority of white middle-class and followed by prohibitions on marriage and reproduction by people with disabilities” (Braddock, D. & Parish, S. 2001, p.39). During the time of eugenics era, people with disabilities were denied even the most basic human rights such as the right to live. Although, not every form of exclusion appears as extreme as the eugenic movement; contemporary forms of exclusion can be as severe as the previous forms of exclusion.

For Jean François Ravaud and Henri Stiker (2001, p.490), “exclusion of disabled people cannot be separated from the way in which a society constructs social cohesion or produces social dissociation”. Thus, it is argued that each society has its own way of rejecting and integrating certain categories. They also differentiate between traditional and contemporary forms of exclusion experienced by people with disabilities in pre-modern and modern societies.

With increasing complexity in modern societies such as division of labor, mechanical solidarity in traditional society emphasizing social whole, gave way to organic solidarity in modern society stressing individualism (Ravaud J.F, Stiker H. J., 2001). In traditional/pre-modern societies or in Gemeinschaft of Tönnies (1979) (in Ravaud J.F, Stiker H. J., 2001), individuals have a predetermined place by birth that is inalterable. Everyone has a fixed place and is part of the society in a certain fashion as long as individuals are not questioning or changing the predetermined place and already assigned role that affects the mechanics of society. In other words, “the individual is a cog in a set of gears” (Ravaud J.F, Stiker H. J., 2001, p.492). The life of dwarf Boruwlaski clearly reveals the exclusion and inclusion experience of the late 1700’s. He was part of the society as Polish Princess’s entertainer until he claimed love and marriage which was not compatible with his predetermined role and resulted in rejection and condemnation afterwards (Ravaud J.F, Stiker H. J., 2001). Unlike traditional societies, the modern society or Gesellschaft of Tönnies (1979) with new advances due to division of labor attributing economic agency to individuals requires them to create their own place and role. Therefore, opposed to pre-determined and fixed places and roles of the traditional society, “process leading to exclusion or integration” becomes important in the modern society.

In addition to the differentiation made between pre-modern and modern societies in the context of exclusion, Ravaud and Stiker (2001) identified a typology of different forms of inclusion and exclusion regarding the social treatment of disability. They categorized exclusion through six models as elimination, abandonment, segregation, assistance, marginalization and discrimination.

"The elimination model" refers to exclude either by putting people with disabilities to death or radically abandoning or withholding of care. "The most extreme and massive massacre happened in Nazi Germany where approximately 200,000 people with mental illness or congenital malformation were exterminated in the hospitals and death camps because of their disability" (Burleigh 1994 cited in Ravaud J.F, Stiker H. J., 2001, p.502). Another form of elimination includes the termination of pregnancy before birth due to impairment. *"The abandonment model"* refers leaving the fate of an individual with disability or severely wounded or deformed to God. It also includes ceasing care or giving the child for adoption. In *"the segregation model"*, the main aim is to distinguish between the insider and the outsider and to segregate the ones who are not conforming to the "normal". However, in this model, Ravaud and Stiker argue that there is a paradox because although the ultimate aim is to integrate the outsiders, they are segregated to be included in a later stage when they are normalized. Another form of exclusion is explained by the *"assistance model"* in which the "individuals receiving help are part of society by the virtue of society's concern for them" (Ravaud J.F, Stiker H. J., 2001, p.505). There is a subordination relationship where the beneficiary is dependent on the benefactor. As a result, people with disabilities are not enjoying equal status as people without disabilities. In *"the marginalization model",* deviation from the norm and rejection by the dominant group leads to exclusion. The main source of exclusion arises from differences and deviance. Excluded ones are expected to act like mainstream to be included. Lastly in the *"discrimination model",* treating equal individuals inequitably becomes the source of exclusion.

Another analysis introduced by Silver (1995), the "monopoly paradigm", can also offer an alternative interpretation and insight into the social exclusion experience of disabled people through stressing hierarchical power relations between disabled and non-disabled people. On the basis of her analysis, it can be argued that non-disabled people with a more powerful position as compared to disabled people restrict the access of outsiders, who are disabled people in this case, to valuable resources such as accessible environments, non-segregated good quality education, well paid decent jobs, benefits, and etc.. In a sense, material and cultural privileges of non-disabled people affect the exclusion experience and it can be argued that their act of restricting access to resources is also fed culturally.

There are different models or paradigmatic approaches to explore the social exclusion experience of people with disabilities and each of them mostly stress multidimensionality and a dynamic character by exploring relevant actors, diverse causes arising from a set of drivers, complex relationships as well as different modes of exclusion. To design adequate policies, considering each component plays a crucial role.

3.3.1 Dimensions of Disabled People's Social Exclusion

In line with previous discussion regarding social exclusion, it is also very common to refer the social exclusion experience of disabled people as multidimensional, interconnected and as a vicious cycle where each dimension affects and reinforces the other aspects. "People with disabilities are often denied the opportunities of full participation in the activities of the socio-economic and cultural system which they are part of" (UNDESA, 2009, p.25).

People with disabilities experience various forms of exclusion arising from diverse and interrelated dimensions such as economic, social, cultural and political. (Bhalla and Lapeyre 1997, UNDP 2011, UNDESA 2009, Sen 2004, Saith 2001). They experience both income related and non-income related deprivations affecting to what extent they can realize their potential and pursue a life in line with their needs and interests.

> "Across the world, people with disabilities have poorer health outcomes, lower education achievements, less economic participation and higher rates of poverty than people without disabilities. This is partly because people with disabilities experience barriers in accessing services that many of us have long taken for granted, including health, education, employment, and transport as well as information. These difficulties are exacerbated in less advantaged communities" (WHO & World Bank, 2011, p.xi).

Appleton-Dyer and Field (2014) state that disabled people are often associated with devalued roles, which can result in a range of exclusionary practices such as discrimination, stigma and low expectancy. People with disabilities are often subject to negative social attitudes, neglect and stigmatization that increase vulnerability and exclusion risks through reducing opportunities. (Elwan, 1999) Most of the case studies cited in Elwan (1999) shows that people with disabilities have lower education and income levels as compared to the non-disabled population. Morris (2001) also voices similar argument;

> "We experience disabling barriers - unequal access to education, inaccessible housing to name just two - which non-disabled people do not face. We experience higher costs of daily living -created by a need for personal assistance, sign language interpreters, supporters, mobility equipment, communication equipment - which non-disabled people do not face."

Burcu (2015) while discussing the cultural representation of disabled people in Turkey states that both the excluded and the excluding ones are parts of the same social setting and cultural perspective plays a crucial role in this process. She asserts that the way cultural context portrays disabled people categorizes them and results in prejudiced attitudes and behaviors. Cultural representation of disability that portrays disabled people as helpless and burden have negative influence on disabled people's participation into social life.

Disabled people severely experience barriers to access income generating activities, employment opportunities as well as material deprivation. "The degree of disadvantage is more severe for a substantial number of disabled individuals compared to any of the other groups including, in particular, on the basis of non-participation in the labor market and levels of family income" (Sloane, P. and Jones, M. 2012, p.128). Even if disabled people are employed, they are working in insecure and low paid jobs that are unable to respond their needs and afford costs associated with disability. Due to material deprivation, disabled people barely acquire necessary assistive devices that ease their lives (WHO& World Bank, 2011) and in most cases social protection systems fail to address additional costs due to disability. Moreover, disabled people are less likely to be recruited in line with their qualifications and they are less likely to be promoted (Schriner, 2001, WHO& World Bank, 2011). However, the economic dimension is not only related with being excluded from the labor market or experiencing income deprivation, but also closely related with being excluded from being perceived as productive and skillful individuals at the society level. Consequently, both access to material resources and access to valued social roles have close connections with each other as well as with the economic dimension.

Although a strong emphasis on economic dimension underlining access to employment or income deprivation is more frequently voiced as compared to other dimensions, it is not possible to separate the economic dimension from the social and political dimension as well as from the cultural system and political economy. A couple of examples to point interconnectedness of disabled people's social exclusion include; unequal access to education affecting possibility to find a decent job, ability to afford extra costs associated with disability having an impact on participation into social life, inaccessible environment restricting mobility and participation in different dimensions or prejudices related with disability influencing social, economic and political participation on equal par with others etc

The political dimension is one of the important aspects influencing the lives of disabled people. For instance, the most basic political right as voting independently is denied to visually impaired citizens in Turkey and such a restriction has profound effects on having a voice and influencing representation as well as acquiring power to demand from the state. Unlike the rest of citizens, who are subject to vote by secret ballot method, the visually impaired citizens still have to vote together with someone else, which makes their voting public.

Similar challenges are also experienced by disabled people while accessing health services. Tufan and Arun (2006) state that most of the people with disabilities are isolated from the society and have no access to even the most basic health services. Lack of qualified personnel with sign language in hospitals or inaccessibility together with lack of guidance with Braille and audio recorded information systems for visually impaired patients are crucial problems restricting the access of people with disabilities to health services (Akbulut, S. et al 2014). Institutional framework treating differently one citizen from the other and unable to respond to the needs also restricts the participation of disabled people in various dimensions. ‟Different institutions within society may sanction and legislate for the selective treatment of different groups or individuals, and define their own criteria for inclusion and exclusion" (Abrams & Christian 2007, p.217).

Restriction on social participation is a common experience for disabled people as well. Inaccessible infrastructure together with prejudiced and stereotyped knowledge results in segregated facilities or separate social places affecting isolation. For instance, lack of accessibility in sport tribunes makes it impossible for disabled people to watch a sports match and share all special moments with their friends and family. Consequently, not only the opportunity to participate equally in social life is affected, but also social ties are torn.

As can be seen from the above examples, there are diverse, interacting and reinforcing dimensions in the social exclusion experience of people with disabilities. To better understand social exclusion of disabled people, it will be beneficial to identify the reasons behind these processes.

3.3.2 Reasons behind Social Exclusion of Disabled People

In previous sections where social exclusion is conceptualized, diverse paradigms and models made it clear that an easy and simplistic way of identifying sources leading to exclusion would be a Pollyannaish optimism resulting in an incomplete picture of disabled people's exclusion experience. Hence, there is not a single cause of social exclusion; instead there are multiple interacting and reinforcing set of institutional, social and cultural drivers making the exclusion process and consequences very complicated.

Since the social exclusion experience of people with disabilities involves more than financial dimension, but also include social, cultural and political dimensions (Bhalla and Lapeyre 1997, Jehoel-Gijsbers and Vrooman 2007), inherently there are diverse sources creating exclusion arising from economic/structural as well as social and cultural aspects.

Geda Jehoel-Gijsbers and Cok Vrooman (2007) in their analysis introduce a useful framework to explore the risk factors of social exclusion both at micro, meso and macro level. The table below offers several risk factors affecting exclusion process at different levels and provide basis for comprehensive sociological analysis.

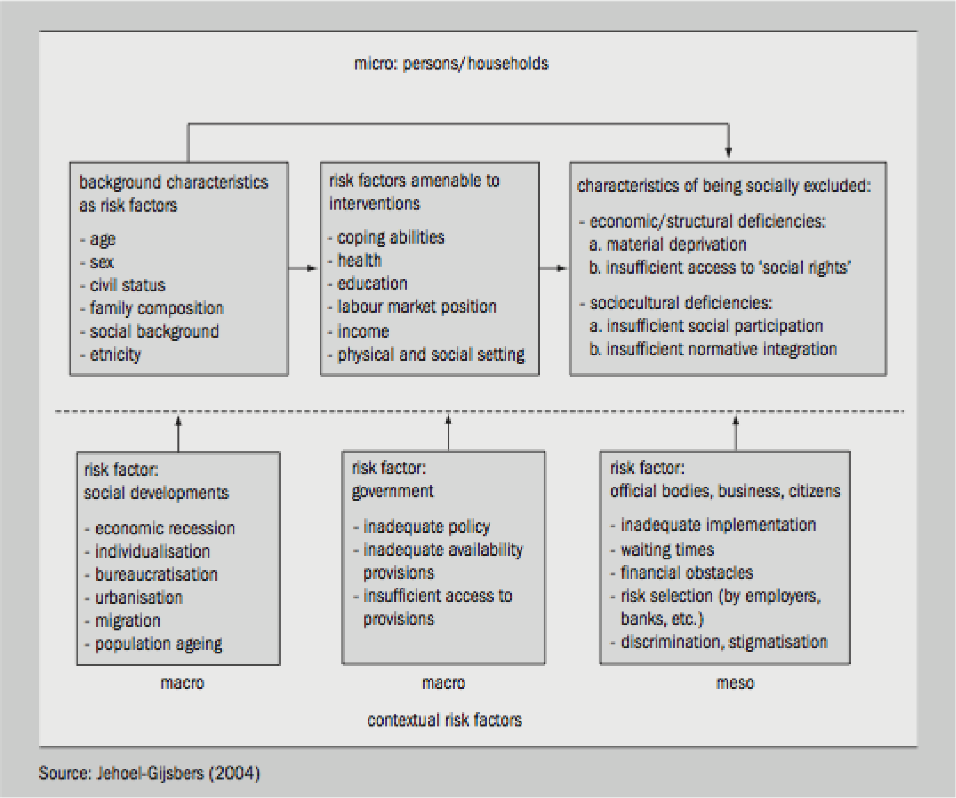


Figure 3. Risk factors affecting social exclusion process

Source: Jehoel-Gijsbers, G. & Vrooman C. (2007, p.19)

Accordingly, gender, age, socio-economic status, class, ethnicity, sexual orientation, severity and complexity of impairment can be named as significant risk factors having impact on the social exclusion experience of people with disabilities.

Old age is a critical factor affecting participation of disabled people. As Elwan (1999, p.35) states "in the developing countries, where the resources are not available, the increasing numbers of elderly people will continue to rely primarily on family and possibly community resources" which makes them vulnerable to exclusion. Gender is another risk factor that affects social exclusion process. Disabled women because of fewer education and employment opportunities are more disadvantaged than disabled men. Furthermore as most of the case studies cited in Elwan (1999) reveal; disabled women are exposed to emotional exclusion more. They are less likely to marry than a disabled man.

In addition to the influence of above stated personal characteristics as risk factors, the interaction of diverse sources such as structural, policy related and behavioral ones also have a crucial impact on whether an individual experiences social exclusion or not (UNDP, 2011, Atkinson & Hills, 1998). To what extent norms and public/private institutions influence or address discrimination through institutional capacity, governmental supports or legislative efforts, how cultural practices affect exclusionary behaviors and to what degree policies respond to actual experience of disabled people can be named as different sources of exclusion.

In terms of institutional framework, unenforced laws or legal framework restricting equal opportunities to disabled people, inconsistent policies and their implementation can contribute to discrimination and the social exclusion of disabled people. UN Human Rights Office’s report on monitoring CRPD (2010) reveals that still; there are visually impaired individuals who are not allowed to open bank accounts due to exclusionary patterns of some banks. Even the simplest activities are restricted for disable people; consequently, they are not seen as equal individuals, but are seen as rather charitable and social responsibility objects and they can only enjoy 2nd class economic as well as social participation. Material deprivation, limited access to education and employment opportunities that restrict pursuing one’s potential, religious and cultural barriers, inaccessible public transportation and social environment excluding disabled people from social participation are among the set of drivers affecting the social exclusion experience (Islam 2015, UNDP 2011).

People with disabilities bear more social exclusion risk directly related with disability or related with their status involving income, health, employment, education, resources, opportunities and assets (UNDP 2011, WHO& World Bank 2011). Bowie C. L. (2005) states that it is equally important to identify how policy makers and policies consider and treat disabled people in order to capture why people with disabilities are subject to social exclusion. Whether people with disabilities are considered as equal citizens or objects of charity directly affect policy design and actual practice.

As Drake (2001) argues, welfare systems through its policies and services can be constraining or liberating for people with disabilities. Economic as well as political transformations directly influencing institutional capacity through questioning of the state’s efficacy, low welfare spending, restructuring of state market relations are all influential on exclusionary process. ‟Key determinants of disabled people‘s experience will be the level of economic development of a society and the strength of its economy, the extent of the welfare state and the residual role of family support, and the role of religious organizations and charities" (Shakespeare & Watson 2001, p.7).

Category based social protection that requires proof of "extreme poverty" to be eligible for disability benefits or allowances certainly reinforces group differences and results in distancing beneficiaries/receivers from benefactors/givers and affect how disability is experienced. Moreover, social prejudices arising from policies stressing, "difference" and "needs based definitions" prevent disabled people to be recognized as people with "abilities" rather than with "disabilities".

At this point, it is crucial to remember that social exclusion of people with disabilities cannot be separated from how disability is socially constructed, perceived and socially interpreted. Associating and constraining some groups within particular roles are determinative in the social exclusion process. Emphasis on "normalizing tendencies" and "normality" frequently encountered in the history of disability plays a critical role in attitudinal and stereotyped practices as well.

> "The difference of disability was perceived as a ground for exclusion rather than a cause for celebration of the diversity of the human family. The greater the tendency to construct everyday life with only the able-bodied in mind and the greater the lack of a physical presence of disabled persons in the mainstream, the more "natural" this assumption appeared to be." (Quinn, G., & Degener, T., 2002, p.23).

The dualist separation between the disabled and non disabled in which the latter is associated with nonconforming to normal and healthy understandings results to a great extent in stigmatization of disabled people. According to Appleton-Dyer and Field (2014), societal perceptions and difference, otherness, understanding of the ideal and perceptions of valued or devalued roles play crucial role in social exclusion. The diagram below sets out the complexity of the drivers behind social exclusion process.

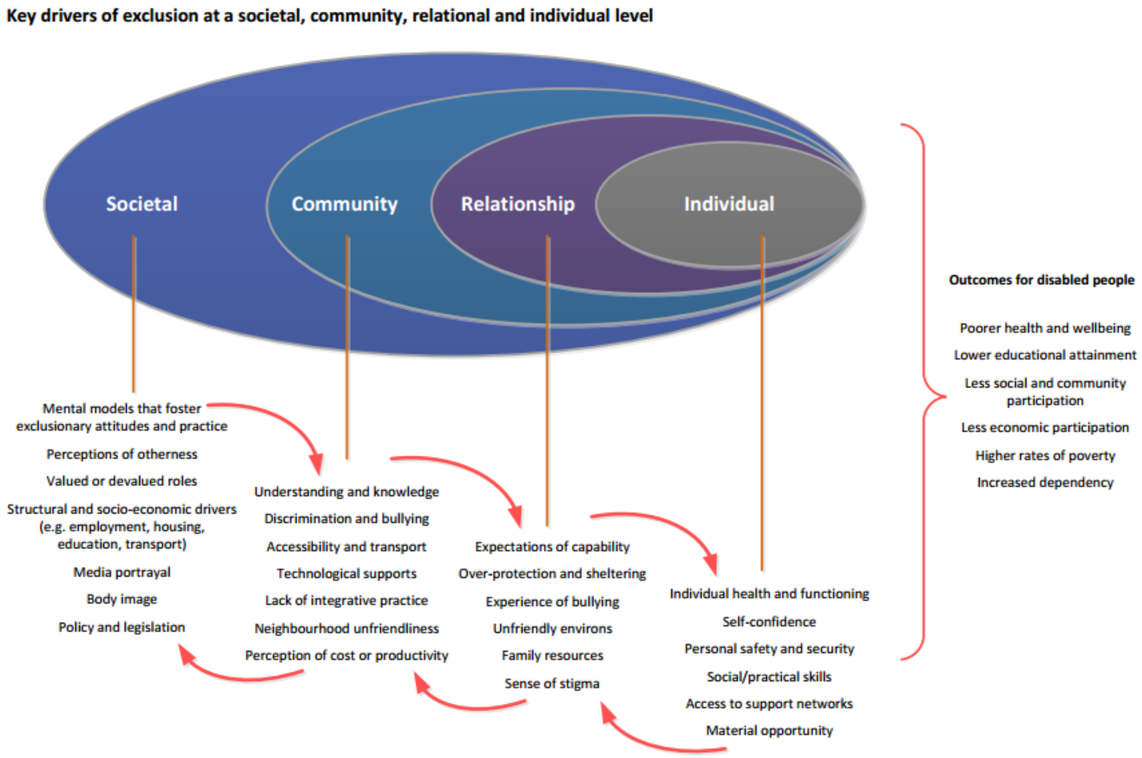


Figure 4. Key Drivers of exclusion at various levels

Source: Appleton-Dyer and Field (2014, p.8)

Social exclusion and societal prejudices are closely related. According to UNDP (2011), those who are subject to social exclusion experience prejudiced treatment; therefore, there is an instrumental relationship between discriminatory treatment and social exclusion. However, not all forms of discriminatory and prejudiced behaviors are easily identifiable. Deal (2007), in his article states that it is possible that people have learnt acceptable behaviors and verbal expressions towards disabled people, thus exhibiting non-prejudicial behaviors, but at the same time holding prejudicial feelings and beliefs which makes it very complex to address. Subtle prejudices may also be the reason of existing exclusionary treatment that disabled people face while enjoying equal citizenship or accessing education, health care, employment or why employers are reluctant to make work accommodations accessible.

Attitudinal barriers are crucial sources of social exclusion and influential on various dimensions (Elwan, 1999). In Turkey the recent survey (2011) based on face-to-face interviews with 241 disabled and 178 non-disabled people in 9 cities as part of

"Prevent Discrimination" project reveals the effects of attitudinal barriers. Accordingly, it is found out that 57.3% of the population is in favor of separate schools for disabled children and 70.3% said they would not want a person with orthopedic disability as their neighbors. (Sabancı Foundation Grant Program Studies, 2012). Additionally, the research regarding "How Society Perceives Persons With Disability" conducted by Administration For Disabled People (ÖZİDA) in 2009 shows that people with disabilities are considered as dependent, destitute, incomplete, in need of normalization, consumers, incompatible, unsuccessful, unable to take responsibility, who exploit their impairment to have their needs satisfied. If they ever succeed something, it is often seen as a miracle. The common attitudes towards disabled people involve pity, denial, exclusion, anger and ignorance. Moreover the research reveals that the most significant obstacle regarding active participation of disabled people to social life is societal prejudice with 45.4%.

Imagery and the way disabled people are represented critically contribute to stigmatization, prejudices and exclusionary patterns as well (Hutchison et al, 2007, Abrams & Christian, 2007, Hevey 1992, Taylor 2008). The portrayal and images of people with disabilities via charity activities and advertisements confirm already existing assumptions that disabled people are inferior, helpless, dependent and needy (Doddington et al. 1994; Akbulut 2012). Consequently, how people with disabilities are represented influence societal attitudes as well as the social exclusion experience and lead disabled people to "find themselves as prisoners of the misconception of others" (Gray and Hahn cited in Swain & French, 2008, p.184). The behavioral as well as linguistic subordination are also influential in treating disabled individuals as passive, helpless and dependent.

> "I can well recall my confusion and anger when, as a teenager, wheeling my father's wheelchair into a cinema, I was asked over his head whether he would like a smoking or non-smoking seat. At 13 it was difficult for me to comprehend why I was being asked to take responsibility for the prime authority figure in my life". (Vincent, 1995 p.20)

Disability has its real meaning in social and cultural context through interaction with other people. Accordingly, cultural meaning attached to disability that involve cultural codes and expected roles about disabled individuals is influential in social exclusion experiences. According to the report on "Disability in Turkish Textbooks" it is very common to encounter prejudices regarding people with disabilities such as deficient, needy, unable, incapable and impotent (Çayır & Ergün, 2013). Prejudiced and negative connotations attached to disability have influence on cultural disablement which categorize people in two mutually exclusive groups and distance disabled people from society.

The report about "Disability in Turkish Textbooks" (2013) reveals that disability is commonly mentioned in chapters related with "difference", which refers to physical difference in a problematical way. Instead of presenting disability as one of the human experiences, marginalizing disability and degrading it to a physical problem becomes a source of exclusion. Hidden or direct messages conveying the message that people with disabilities should be normalized or portraying disability as a problem to be solved by cash transfers (allowances and charity campaigns) in a merciful manner affect social exclusion experiences.

According to Fraser (2007), injustices have variety of forms affected by a variety of means such as political economy, institutionalized cultural values and combination of both. Her analysis is also valid and explanatory for disabled people's situation where culture and political economy is very influential on their exclusion experience. Besides, the disadvantaged position of the disabled people concerning political participation such as being less represented or not represented at all can restrict opportunities to have voice in discussions about justice. (Fraser, 2007).

Herein, it will be beneficial to recall Bhalla and Lapeyre (1997) who attract attention to complex relationships between different dimensions becoming a source of exclusion and exacerbating different forms of oppression. They assert that having an economically powerful status can influence both voicing, exercising political rights as well as liberties and makes it easier to demand from the state authority.

> "By virtue of their incomes and assets, the rich are much more powerful and influential than the poor who, for lack of economic means, education, and so on, are poorly organized. Thus economic might enables the rich to extract from the State, civil and political rights and liberties. One may, therefore, argue that economic resources enable access not only to economic goods and services but also to political goods like freedom and the ability to influence economic policies" (Bhalla and Lapeyre, 1997, p.418).

The extent to which organizations of people with disabilities are involved and advised in decision-making as well as designing coherent policies taking disabled people's suggestions into account are also crucial features regarding social exclusion (Shima and Rodrigues, 2009).

Superficial policies unable to identify and address the root causes of exclusion can further exacerbate the social exclusion experience and emerge as a source/cause of exclusion in other forms of deprivations. Nancy Fraser's distinction between affirmative and transformative remedies provides a useful insight about deprivation in one dimension becoming a source of exclusion in another dimension (Fraser, 1995).

"Policies to reduce social exclusion may need to use multiple methods of detection and multiple approaches to tackling exclusion in order to respond to the diverse forms it can take" (Abrams, D., Christian, J. and Gordon, D. 2007, p.xv). Accordingly, overlooking cultural representation and misrecognition creating disadvantages result in prioritizing palliative redistributive remedies addressing economic deprivations encountered by people with disabilities. Nevertheless, exclusion as being defined as a process with multidimensional and overlapping deprivations needs to be addressed through well balanced and coherent policies which do not "pretend to address", but take the redistribution, recognition and representation needs of people with disabilities into account.

3.4 Relationship between Charity and Disability

As discussed earlier in the history of disability, either due to institutional barriers or attitudinal ones arising from diverse set of drivers, disabled people are denied equal access to social, economic and political life preventing them from realizing their potential. Additionally, structural and cultural factors also affect equal citizenship understanding and contribute to the emergence of charity as a part of disability in varying degrees. During early periods of urban industrialist capitalism, charity happened to be the sole source of income for disabled people or entitlement to charity appeared as a pretext for their removal from the social community (Stone 1984, Oliver 1990, Soldatic and Meekosha, 2012). In UK, due to industrial capitalism as well as the consequences of economic system that weakened traditional support systems such as community, family and religious institutions, the disadvantaged position of the excluded ones such as disabled people and their needs were mainly left to charities up until the establishment of local authorities (Shakespeare 2000, O'Halloran, 2008). Meanwhile in the Ottoman Empire, there were also foundations enhanced with Islamic ethos aiming to help those in need including the disabled people (Bezmez & Yardımcı, 2010).

When the welfare state emerged as the primary responsible welfare provider to its citizens, the role of charities and the charity model of disability became subject to some changes; however, their role did not drastically diminish in providing support to disabled people. As argued by Shakespeare (2000), once the failure and deficits of welfare states were identified and became obvious in the 70's, there were some initiations to foster social change. Especially since the 70's, charity appeared as a political ground to mobilize disabled people to demonstrate against charity campaigns. By voicing the slogan: "rights not charity", disabled people aimed to attract attention on barriers preventing equal citizenship and demanded their rights instead of charity (Shakespeare 2000, 2006, Swain et al 2003, Taylor 2008, Morris 1991).

Although the recent political mobilization of disabled people and emergence of the social model of disability challenged the idea of treating disabled people as objects of charity, Swain et al. (2003) states that legacies form Victorian philanthropy still endures and can be even found today in spite of social and historical transformations. Moreover, the neoliberal shift has also a crucial impact on how charities sustained their importance. For instance, changes in the role of state authorities that acts as the funding agency and purchase from the market as well as voluntary organizations, once again emphasized the role of charities in welfare (Shakespeare, 2000). Buğra (2009) also supports this argument by stating that during the 90's, when failure of market to address problems of employment as well as poverty became apparent, voluntary initiations and organizations reappeared as important players.

The neoliberal shift adopting public programs that move the attention from social to individual had also crucial and reverse influence on stressing a citizenship conception underlining responsibilities and charitable giving. Moreover, in countries like Turkey where a strong welfare state understanding has never been completely established, the importance of informal support and charities did not drastically change (Bezmez & Yardımcı, 2010). Instead, strict eligibility criteria for entitlements due to neoliberal adjustment policies led to an increase in importance and dependence on charity more and more. New forms of conservative benevolence started to replace the social state.

> "In general, a paternalistic model of help predominates, in which the priorities and practices are agreed by people who are not those in need of support. And the very need for charitable assistance may often be due to the shortfall of mainstream provision or the failures of social organization" (Shakespeare, 2000, p.52).

In today's context, it is not wrong to argue that the increasing importance of charity appears as a useful mean to disguise systematic and structural inadequacies (Koray, 2005, Çelik, 2010). Therefore, the main focus of this section will be on charity in the complex relations of disability and social exclusion.

3.4.1 Exploring Charity in the context of Disability

Charity is a widely debated concept within the context of disability. As discussed earlier, socio economic injustices originating from political and economic structures as well as the cultural representation of disability produced and reproduced via discourse, language and symbols are important elements of the social exclusion process (Fraser, 1995), and charity with its controversial nature is a critical player in this complex and dynamic process. Moreover, charity involves both income related aspects such as motivation to address material deprivation as well as non-income related features such as humanitarian motive, religion and cultural influence. Throughout the literature review, different perspectives elaborate the complex role that charity plays in disability as well as in the dynamic nature of social exclusion.

According to Cambridge Dictionaries Online, charity has multiple meanings that involve "kindness towards other people or money, food and other help given to people or an official organization that gives money, food or help to people who need it". Henri Jacques Stiker (2001) states that charity is derived from the Latin word caritas meaning disinterested love, and there are strong references to charity in the

Bible and other religious thought. Hence, there is a strong connection between religion and charitable activities.

Not only Christianity, but also Islam has strong reference to charity by stating that those having property are obliged to give some portion of their wealth to those in need. But according to religious thoughts, in order not to expose superiority of one side over the other, the charity relationship is supposed to involve anonymity. For instance, according to Islamic practices, charity should be so anonymous that the left hand shouldn't be aware of the benevolence performed by the right hand. But in today's world, where individual responsibilities, civil initiative and charitable giving are underlined more and more, people are competing to show their kindness, power and expose their generosity as much as they can. ‟Celebrities gain positive publicity or atone for their mistakes by high-profile support for good causes" (Shakespeare, 2006). It has also a role in the refection of status and power. In Turkey, the telethons to raise funds for disabled people that gained great social support are good examples to show off generosity in the present day.

Robson et al. (1997 cited in Shakespeare 2006, p.166) explains the motivation behind charity as "caring for others, mutual help among those in similar circumstances as well as solidarity to achieve change through empowerment and equality". When the motivation behind charity is expressed in such a positive and socially acceptable way, it seems hard to be criticized. However, charity activities have been subject to various criticisms that relate to both distributional as well as relational aspects of the social exclusion concept. As stated earlier, charity has been a powerful source in gathering a disability movement around a shared activism that challenges the role of charities in exclusionary patterns. However, in some cases, this activism critiquing charity resulted in blaming disabled people for being ungrateful, cynic and unthankful. As in the words of Shakespeare, (2000, p.58) "it is very difficult to combat oppression when it comes in the form of apparent generosity".

The initial intention regarding charity is to provide support and respond to material deprivation of those in need. Mainly in this relationship, givers aim to address the problems of those in need that are people with disabilities in this context. Most often, charity has a role to complement the government and respond to failures of insufficient governmental provisions (O'Halloran et al. 2008, Shakespeare 2000). However, "material help from charities is dependent on the charities' definitions of what constitutes a "deserving case" and this undermines disabled people's rights to the things which make a reasonable quality of life possible" (Morris, 1991, p.138). Moreover, inability to meet deserving criteria also results in exclusion of some portion of people with disabilities not able to satisfy a deserving case, but who still need support.

At this point, it is crucial to refer the medicalization tendency of charities on disability, which is exclusively criticized by many disability writers (Morris, 1991, Shakespeare 2000, 2006, Drake 1996, 2004, Taylor 2008, Barnes 1992, Campbell 1990, Waltz 2012, Doddington et. al 1994, Hevey 1992). "Disability charities function to construct a medical model of disability and place themselves in a role of care, cure and control in relation to it" (Waltz, 2012, p.220). In a sense, bodies with impairment are turned into commodities owned by charities to better market and increase funds. Impairment is presented in such a way to frighten non-disabled individuals and remind their own vulnerability (Shakespeare, 1994) which contributes to the construction of the normality myth.

Herein, it is beneficial to recall Shakespeare's (1994) analogy between pornography and charity. He suggests that the way disabled people are objectified in charity advertisements has similarities with objectification of women in pornography where the main focus is on passive and available "body". According to him, while pornography exaggerates sexual parts of the body, charity performs the same exaggeration by exposing "flawed" parts of the body. "In each case, the viewer is manipulated into an emotional response: desire in the case of pornography, fear and pity in the case of charity advertising" (Shakespeare, 1994, p.288). Moreover, Morris also contends "non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity" (Morris, 1991, p.192).

The main criticism about charities arise because of detaching "disability" from unequal power structures, social, economic as well as political environment and presenting it as a personal problem. As Drake (1996) contends, charities by employing the medical model of disability, individualizes the problems faced by disabled people, and in order to attract attention and motivate non-disabled people to donate, stimulation of pity together with sympathy and fear is promoted. Portraying people with disabilities in a stereotyped way as a homogeneous group with a passive, powerless, useless, needy image and objects of mercy is a way of depoliticizing disability (Taylor, 2008, Shakespeare 1994, Barnes 1992, Campbell 1990, Waltz 2012,). Moreover, as Shakespeare (2000, p.57) asserts "helping motivated by pity is an inferior substitute for social inclusion and citizenship".

> "Disabling stereotypes which medicalize, patronize, criminalize and dehumanize disabled people abound in books, films, on television, and in the press. They form the bed-rock on which the attitudes towards, assumptions and about and expectations of disabled people are based. They are fundamental to the discrimination and exploitation which disabled people encounter daily, and contribute significantly to their systematic exclusion from mainstream community life. It is also clear that recent attempts by some elements in the media to remedy the situation and 'normalize' disabled people will only partly resolve the problem" (Barnes, 1992, p.39).

In literature, though the main emphasis is on the way disabled people are represented as pitiful, destitute and incapable individuals, the recent shift in positive imagery representation can also be a threat and source of oppression by promoting a "normalized" disabled people image (Morris 1991, Campbell 1990, Taylor 2008, Drake 2004). Portraying disabled people as heroes or heroines "despite their impairment" implicitly gives the message that in order to minimize exclusion; disabled people should be like normalized disabled heroes. "Disabled people have become more oppressed by positive imagery than they were by the apparently negative or stereotypical imagery" (Drake, 2004, p.102). As Drake (2004) argues, a distinction between good and bad cripple has been made and although the language has changed, the politics behind it remain untouched.

David Hevey's (1992) well-known book "The Creatures Time Forgot" also provides meaningful insight to how charity advertises disability. Hevey (1992) explores the charity system by identifying 3 stages in which disability is represented. He contends that the main orientation in charity is "to sell fear and to promote a brand not to buy, but to buy your distance from". Therefore, the use of images enhancing pity and fear is logical and common because it works best to promote buying that distance. In the first stage, two opposing concepts involving a use of a negative image and a positive text are promoted. By that way, at first, a dependent and hopeless image is transmitted and afterwards by employing a positive text charity appears as a solution. Hence, in the 1st stage, there is a combination of a negative image representing the past and a positive text directing the hopeful future through charity. Whereas, the 2nd stage called as attitude change by Hevey pioneers social change without political action that leaves the complex system of oppression unchallenged and promotes new representations and identities. In the final 3rd stage to emphasize the importance of charity, a positive image and a negative text combination is used. Disabled people performing "normal activities" like "normal people" represents the positive image; whereas, all this progress could not have been accomplished without charity appears as the main message. Offering charity as a vital solution to disabled people's exclusion and to help them become "normal disabled people" is clearly underlined. Instead of stimulating people to reconsider and challenge how they perceive disability and oppression arising from disability, charity uses positive and negative images and texts to present itself as the major solution to disablement.

Presenting charity as a major solution to disablement and satisfying a "feeling that problems are solved" are significant features in social exclusion-disability relationship. Therefore, those who criticize charity are not only very critical about the way charity promotes itself and portrays people with disabilities, but also how charity is presented as a useful means to an end. Although it is widely voiced that increasing involvement of disabled people in the charity world through collective self-advocacy will have positive transformations (Shakespeare, 2006, Waltz 2012), Hevey has doubts about this view because of charities' inability to address the main problem; that is "social disablement". "Charity advertising ultimately fails because it cannot acknowledge, let alone solve, the issue of social disablement" (Hevey, 1992, p.51).

To a great extent, pitiful disabled people are serving as a means to make non-disabled people feel good and more powerful. In such an asymmetric relationship created or enhanced by charity, it is not possible to identify two equal parties. Instead, there is an implicit domination of non-disabled individuals over disabled people. Charitable activities involve an asymmetric, unequal giver-receiver relationship where a more powerful and rich party addresses the less fortunate ones experiencing a hardship situation (Morris 1991, Shakespeare 2006). At this point, it is important to recall Kelly (2001, p.396) who states that “dominance of one person over another is argued to turn impairments into disability; consequently, disability itself becomes a form and a source of exclusion”. Moreover, Doddington et. al. (1994) attracts attention to today’s value system where people who are considered more capable are the ones better accepted. Therefore, although promoting “dependence on charity” through an asymmetric relation as the major solution to achieve positive outcomes stimulates non-disabled individuals to donate, it is ultimately very problematic because of creating unintended side effects by contributing to prejudices and stereotyped patterns about disabled people.

Since disabled people hardly ever exist in mainstream culture other than being presented as needy, ill, pitiful and destitute through charities (Barnes, 1992), strongly voiced criticism about charities seems logical as being the only powerful mean representing disabled people in society. Hence, charity activities have a significant and undeniable role in shaping cultural representations of people with disabilities, which reflect cultural subordination. As a result, it is an influential source in the creation of disability culture (Shakespeare 2006, Morris 1991, Taylor 2008, Drake 1996).

Additionally, Drake (1997) attracts attention to the dominance of non-disabled individuals as another crucial feature about charity in the context of disability. “Charitable action and the evolution of government social policy have all too frequently reflected the hegemony of non- disabled people” (Drake 1997, p.644). The dominance of non-disabled reveals itself in their authorship of disability equaling it with dependency. They avoid presenting disabled people as ‟subjects”, but mainly transmit ‟help us to help them” message in which they enhance dependency on them by appearing as capable individuals ‟who know how to help those who cannot help themselves” (Campbell, 1990, p.2). ‟The traditional charities that purport to empower disabled people actually disable them, may usurp their voice and can block access to resources that could be put to much better use” (Drake, 1997, p.643).

Herein, it is valuable to recall Morris (1991) who explains how charity sets its own priorities by monopolizing and restricting power given to disabled people. Charities prefer to help disabled people through providing necessary equipment rather than giving the money they have collected. Consequently, what people with disabilities need and want are almost always determined by others –usually guided by non-disabled hegemony- who do not give disable people any opportunity to choose for their needs.

As a wrap-up, referring to Shakespeare’s (2006) analysis of charity will be beneficial to explore charity in the context of disability. He elaborates charity from 3 different perspectives; differentiating charity as symbolism, charity as provider and charity as organization. ‟Charity as symbolism” bears a cultural message reinforcing dependency, helplessness and individualization of disability in which a ‟feeling that problems are solved” is satisfied. ‟Charity as provider” elaborates activities and services of charities that differentiate one particular type of impairment from the others and provide segregated forms of responses. In such a segregated approach, the dominant emphasis is on particular impairment and leave shared oppression as well as political emphasis untouched. ‟Charity as organization” underlines deficiencies of governance, ethos and profile where a differentiation between organizations ‟for” and organizations ‟of” is underlined. Hegemony of non-disabled people claiming to know what is best for disabled peers, better and well funded ‟organizations for” acting as professional businesses that satisfy their needs instead of their target group are among prominent features.

However, Shakespeare (2006) despite acknowledging validity of some aspects of above-mentioned criticism believes that in today’s world, charities have also changed and addressed these critics. He further suggests that motivation behind charity can be a good source to respond the complex needs of disabled people and improve their lives on the condition that while performing charitable activities dignity and rights of disabled people are respected. Instead of voicing ‟rights not charity” slogan, Shakespeare advocates ‟rights and charity” because charity is not a substitute for rights and both of them can co-exist. According to him, if encouraged properly in the right direction, charity can be “radical, inspiring and world changing”

(Shakespeare, 2000) and can provide benefits to many disabled people. A world in which charity complements rights is a better world (Shakespeare, 2006).

As elaborated in this section, there are complex and interacting relations in need of consideration while exploring charity in the context of disability. In the next section, structural and cultural factors behind charity are discussed.

3.4.2 Structural and Cultural Factors behind Charity

Similar to the social exclusion concept, desire to address material deprivation as well as cultural, religious and humanitarian motives are influential in engaging in charitable activities. For that reason, there are multiple, interacting and reinforcing set of factors enhancing the role and effect of charity in the context of disability. Structural factors, political economy and social/cultural drivers are influential in determining the importance of charity. To offer a comprehensive approach, identifying the underlying causes and possible strategies are equally important.

Firstly, it is important to refer to the institutional capacity as well as the state policies as a powerful source in shaping the role of charity about disability. "State funding of responsive formal support services is an important element of policies to enable the full participation of persons with disabilities in social and economic life" (WHO& World Bank, 2011, p.137). However, neoliberal transformations urge public policies to limit their target groups and restrict eligibility to social entitlements. Social welfare transformations that restrict the role of state in responding the needs of its citizens had crucial impact on leaving individuals with their own risks and on worsening material deprivation. "Governments see equality as limited by their need to contain spending, and so tend to not to talk about entitlements but rather discretionary benefits" (Rioux & Valentine, 2006, p.48). Accordingly, governments become less active in response to most disadvantaged groups and emphasize an individualized focus that underlines mutual obligation. Mutual obligation view is satisfied either by requesting more and more active disabled in the employment arena (Soldatic and Meekosha, 2012, Yates and Roulstone, 2013) or by requesting more and more passive individuals exposing their needy profile.

Additionally, to limit the target group, practices differentiating one group of people from others are preferred more. "At institutional level, different institutions within society may sanction and legislate for the selective treatment of different groups or individuals, and define their own criteria for inclusion and exclusion" (Abrams & Christian 2007, p.217). The legal framework as well as selective practices are influential in restricting equal opportunities and appear as important sources in determining the role and involvement of charity in the context of disability.

Herein, it is also useful to refer to the political economy of charity elaborated by Buğra (2009). She argues that manipulating irregular aid is easier and there is more political and economic gain without regulated, transparent and regular social reliefs. Therefore, creating a relationship of gratitude due to the clientalist nature of charity appears more beneficial. Based on her analysis, when a "benefit in kind" is distributed, not only the person who receives aid is happy, but also those taking place in the supply chain of that aid are benefited from this business like system. Consequently, by differentiating social state from state charity through visible, temporary and populist aids, both who receives as well as the ones who take part in the supply chain of aids are satisfied.

The profile of NGO's in the context of disability and relationship between the state and NGOs are significant sources whether charity plays an important role in disabled people's lives or not (Bezmez & Yardımcı, 2010). The extent to which disabled people are gathered around shared activism in politicizing disability through rights based approach or breed a charity based orientation can be named as crucial factors affecting the degree of emphasis given to charity. Besides, governance and activities of NGOs, dominance of non-disabled people in setting priorities, and reflecting their agenda as well as better funding opportunities in favor of "organizations for" as compared to "organizations of" have influential role as well (Shakespeare 2000, 2006, Drake 1997).

Another important source behind charity is how disability is culturally understood. As discussed earlier, in disability conceptualization, there are diverse ways of perceiving disability and depending on how it is perceived different responses emerge. When disability is seen as a stand alone issue, an individual deficit or pathology, disabled people become objects of medicine and they are either treated as individuals in need of cure or as dependent individuals in need of care who should be addressed through charity (UN Human Rights Office, 2010). Medical dominance in disability by detaching it from unequal power structures, social, economic and political context still persists in some spheres (Rioux & Carbet 2003) and appear as a powerful source in promoting charity in the context of disability.

In addition to above-mentioned features, social construction of disability has crucial impact on marginalization experienced by disabled people as well as from which perspective they are seen. The portrayal of disability and societal interpretation of disability experience directly affect stereotyped and negative attitudes towards disabled people. Through socially constructed, learned and shared meanings attached to disability, people with disabilities are presented as others or inferior peers who are not conforming to the “normal” world (Hannon, 2007). Social interpretation of subjective disability experience constructs social expectations about disabled individual’s autonomy, capabilities and functional independence and shapes the degree of charitable gaze in disability.

Since disability is at the same time a cultural concept and meaning attributed to disability is shaped by other people’s reactions and vice versa (Burcu, 2011), how people with disabilities are culturally represented and portrayed as well as religious motives (Bezmez & Yardımcı, 2010) values, attitudes and prejudices have impact on stimulating charitable activities.

As a conclusion, both the distributional aspects involving socio-economic injustices originating from political and economic structures and the relational aspects such as cultural representation of disability are important elements behind the exclusion of disabled people, which charity is a critical part of.

CHAPTER 4

The DYNAMICS of CHARITY, DISABILITY and SOCIAL EXCLUSION RELATIONSHIP in the TURKISH CONTEXT

> “It is much easy to have sympathy with suffering than it is to have sympathy with thought.”
> Oscar Wilde – The Soul of Modern Man under Socialism

In this chapter, the data collected through interviews of respondents and NGOs are analyzed in order to reveal certain priorities, patterns and trends about the relationship between disability, charity and social exclusion. With regard to the main aim of this thesis, structural and cultural factors that affect the dominance of charity in disability and the effect of charity activities in the exclusionary processes are elaborated by analyzing experiences and opinions of people with orthopedic disabilities.

Studying charity targeting disabled people in the Turkish context clearly reflects how society integrates disability into social and cultural knowledge and how the set of different structural and cultural factors interact with each other in determining disability experience. To reveal the significance of charity activities in the lives of people with disabilities, the cultural and structural factors affecting the role of charity are analyzed as well.

In the first part, structural factors such as individualization of oppression through charity system incorporated into state institutions, welfare regime in Turkey, strong medicalization tendency, political economy of charity, legislative framework involving discriminative provisions among disabled people and the role of disability related NGOs are identified and explored as prominent features. In the second part, cultural factors as cultural representation of disability, religious motives, agency and how disability is perceived in the society are discussed to reveal complex interplay between charity, disability and social exclusion. In the third part, how charity activities worsen socio-cultural exclusionary processes is revealed by specifically focusing on the interviewed NGOs’ charity activities and the experiences of respondents.

Lastly, institutional framework as well as cultural practices behind charity provide valuable source for social policy discussions and recommendations that are elaborated in the final part.

4.1 The Structural Factors Determining the Significance of Charity Dominance in Disability

In the past “disability” played a crucial role in distinguishing deserving from undeserving poor, but today as a result of complex social, political and economic relations further stratification within disability determines and identifies who is “disabled enough” to deserve and who is not “so” disabled to enjoy rights and privileges associated with disability. (Stone, 1984, Soldatic and Meekosha, 2012) With neoliberal effect and dominance of “work enforcing welfare” understanding in order to address financial worries and differentiate truly disabled from work-able ones, strict differentiation even within the previously labeled deserving categories through medical evaluation and strict means testing has rationalized and presented as necessary. Structural context involving welfare regime, Turkish disability policy, medicalization of disability and the role of NGOs provides significant insight into multidimensional forms of social exclusionary experiences and affect the dominance of charity in disability.

4.1.1 Welfare State in Turkey and Individualization of Disability Oppression

Firstly, in this study it is important to refer to the institutional capacity, legislative framework as well as state policies as powerful sources in shaping the role of charity in the context of disability. But before exploring above-mentioned factors in detail, it is beneficial to discuss Turkish welfare regime because welfare systems are crucial determinants of how disabled people experience disability, social exclusionary processes related with disability and the role of charity in this dynamic relationship.

As Drake (2001) argues, welfare regimes through their provisions can be emancipatory or constraining for disabled people. In the past “disability” played a crucial role in distinguishing deserving from undeserving poor, but today as a result of complex social, political and economic relations further stratification within disability determines and identifies who is “disabled enough” and who is not “so” disabled to enjoy rights and privileges associated with disability. Welfare systems through various mechanisms such as strict means testing programs, medicalization tendency, work enforcing welfare understanding and individual centered approaches have great influence on providing or restricting opportunities for disabled people. Therefore, it is crucial to discuss welfare system in Turkey and its effect on the dynamic relationship between disability, charity and social exclusion.

Pursuant to political economy transformations due to neoliberal effect in the world, Turkey has experienced similar changes regarding its political economic structure as well. In Turkey, already lately developed welfare understanding having similarities to the Southern European Model (Ferrera, 1996) that adopts strong emphasis on familial support mechanisms, is further affected by the neoliberal era emphasizing individualization of oppression. The discourse that “everything should not be expected from the state” becomes the motto in times of ineffective presence of state and there has been an increasing tendency to point individual responsibilities, civil initiatives and informal networks to overcome exclusionary processes as well as its consequences.

Turkey is governed by AKP (Justice and Development Party) since 2002. As the governing party for 14 years in Turkey, AKP’s approach is defined as “liberal residualism flavored with social conservative values with a significant emphasis on family and communal solidarity” (Buğra & Keyder, 2006, p.213). Its social policy orientation appears as “an amalgam of neo-liberalism with social conservatism” (Buğra & Keyder, 2006, p.222). Although liberalism and conservatism are categorized as two opposing concepts both ideologically and philosophically, indeed they complement each other in the neoliberal era (Çelik, 2010).

In Turkey, harsh conditions arising from a market driven economy that seriously affect people with disabilities are addressed by philanthropic motivation emerging from a conservative social policy orientation. According to Buğra & Keyder (2006), liberal-conservative tendency together with Islamic charity notion describe best the social policy orientation in Turkey. Rather than adopting a rights based universalist approach with an emphasis on equality of citizenship, “charity based system of social policy” inheriting Islamic ethos of Ottoman charity (Bezmez &Yardımcı, 2010, p.607) is preferred because of its quick response, less systematic, non-standardized, clientalist nature and immediate visibility in terms of its political gain. Moreover, state’s ineffective presence let civil society engage in acting for disadvantaged position of disabled people and undertake state’s responsibilities to some extent. Consequently, a new version of conservative benevolence emphasizing individual centered approach has started to replace social state and its instruments in Turkey (Çelik, 2010).

In line with the arguments of Çelik (2010), this study identifies and confirms similar trends regarding privatization of disadvantages and state’s limited and passive engagement in responding its disabled citizens. Interviews conducted with NGOs reveal that except one of the interviewed NGOs, all of them have been contacted by state institutions, politicians as well as municipalities in order to respond personally to the needs of disabled individuals who had chance to voice their requests privately.

NGO representatives’ statements show that they are asked to act as assistive device intermediaries by the state to satisfy personal needs of people with disabilities. Hence disabled people who are lucky enough to voice their requests and reach politically powerful parties are taken into consideration and meet their needs through informalized and institutionalized charity system that is integrated into state institutions. Rather than addressing disabled people’s collective problems by legislative efforts and policies satisfying categorical universality, targeting individual oppression becomes the beneficial objective when conservative benevolence replaces social state.

> “We have received requests from municipalities, the Prime Ministry and the Presidency. Following the assessment of requests as well as social, medical and financial assessment of applicant, we have provided wheelchairs by funds raised from our campaigns”. (NGO 1)

> “We have received requests related with assistive equipment needs of disabled people from state, especially from the members of parliament.” (NGO 2)

Similar experiences are also expressed by the rest of the interviewed NGOs. Charity system incorporated into state institutions *(talep takip sistemi)* by formalizing personal requests submitted to politicians, politically powerful parties and ministers use state's capacity to meet individual needs and eventually provide political gains. The requests of state institutions conveyed to NGOs, serve ultimately the purpose of government policy by addressing deficiencies of state in a personalized manner. The charity system by using disability related NGOs as subcontractors further enhances and promotes individualization of disability oppression and makes disability related NGOs become important structural players in the complex relationship between disability and charity.

Above explained process confirms Rioux & Valentine (2006) who argues, "the privatization of the disadvantage justifies and perhaps even mandates a restrictive or passive engagement in its resolution". Charity system incorporated into state institutions not only eases economic burden on the state and provides political gains but also encourages a citizenship conception stressing personal efforts and leaving major responsibilities to citizens.

With the neoliberal effect and dominance of work enforcing welfare understanding in order to address financial worries and differentiate truly disabled form work-able ones, strict differentiation even within the previously labeled deserving categories through medical evaluation and strict means testing has rationalized and presented as necessary. As argued by Rioux & Valentine (2006), the privatization of oppression results in adopting an individual level unit of analysis and emphasis on citizenship conception stressing domestic responsibilities, which rationalized work promoting welfare provisions and state's passive engagement. "The ongoing reorganization of state structures of relief, or welfare, is to reinforce work norms." (Piven and Cloward, 1993 cited in Soldatic and Meekosha,, 2012 p.199) In Turkey the recently issued Circular on "Procedures and Principles Regarding Enhancement of Social Aid and Employment Relationship" published on 14.04.2014 underlines similar concern by underlining the danger of dependency culture and voices that social aid should be transferred in a way to promote employment. Accordingly, "work-able" ones who are projected as people with an extent of disability between 40-69% are required to register Turkish Employment Agency (İŞKUR) that is the responsible organization for directing them towards suitable vacant posts. In Turkey, considering disability as an "administrative category" (Stone, 1984) is still valid and persists in order to categorize who belongs to a distributive system based on work and who to a distributive system based on need. Financial worries together with dependency culture discourse emphasize individuality and influence the framework of policies as well as legislative efforts to a great extent.

In this study, when respondents are asked to share their opinions about state's disability policy, they critically refer to "state charity" and state's inability to respond to the needs of its disabled citizens via a national disability policy based on citizenship rights. Lack of adequate disability policy and institutionalization of "charity based system of social policy" (Bezmez &Yardımcı, 2010, p.607) have influence on the degree of individualization tendency among disabled people. This study shows that insufficient state policies enhancing privatization of oppression are also internalized by disabled people. Younger disabled people tend to internalize individualization of their disadvantages relatively more than older ones and try to tackle their problems on their own through informal support mechanisms.

> "I am trying to satisfy my needs with the help of my relatives, kith and kin. From time to time, I need financial support and I borrow from my close friends" (Elif, F, 26 years old)
>
> "State's disability policy, if there is any, proves that there is state charity, not a social state. State provides very limited assistance so that its disabled citizens are dependent. Then a vicious cycle of "I will help but vote for me" is created" (Ezgi, F, 33 years old).
>
> "In fact state's disability policy and public resource available to disabled people is the best medium to prove social state understanding. But there is not a social state, just that it's written that there is." (Demir, M, 24 years old).
>
> "The best expression that describes state disability policy in Turkey is 'pretending' (that there is)" (Ezgi, F, 33 years old).
>
> "I have a disabled friend who is civil servant. Once he needed to renew his orthesis but his income level was not sufficient to afford a new orthesis and state aid was not enough to cover expenses either. Hence he is neither eligible for NGO charity due to his income level which is also insufficient to meet his needs, nor does state cover expenses for his assistive device. However there are other means to meet disabled people's needs. But most the disabled people do not know how and where they can find resources. For instance, Governorship allowances as well as district governorship's social aid and solidarity promotion fund can provide resources. Disabled people can satisfy their needs through other sources as well, but they do not know how… Disabled people should be able to chase after available opportunities" (Ali, M, 30 years old).
>
> "State is apolitical concerning its disabled citizens. There is not any disability policy in Turkey. Instead, the current state disability policies even prevent the development of disability rights movement. State remembers its disabled citizens from election to the next election and pretends to care for disabled people" (Aslı, F, 41 years old).

> “Disabled people instead of joining forces to voice strong political demands, look after their interests and compete for scarce resources. In the end they are thankful for what they should already have had as their rights.” (Ezgi, F, 33 years old).

As a result of ineffective state policies promoting informal networks, encouraging familial solidarity and incorporation of informal support mechanisms into state, people with disabilities are desperately left alone with risks, made more dependent and motivated to address financial concerns through traditionalistic and informal networks.

> “Disability appears a familial phenomenon and responsibility. It imposes more responsibility on family than state. Family members are always anxious about the future of their child and they feel obliged of taking care of their children” (Sevgi, F, 45 years old)
>
> “As a citizen, I feel alone. I wish to die with my mother in a car or a plane accident.” (Deniz, M, 44 years old).
>
> “If you do not have close relatives, if you are not a celebrity or if you do not have enough income, you are a living dead. Either you stay at home all the time or become a slave of the disability related NGOs”. (Beste, F, 42 years old)
>
> “If I did not have enough income and wealth, I would have to rely on charity campaigns. Because either you satisfy your needs through personal wealth or you are doomed to what state provides you even if it does not respond to your needs. Or you need to apply to NGOs and charity campaigns”. (Aslı, F, 41 years old)

This study reveals that charity system integrated in state institutions as a form of passive engagement, rather than challenging deep structures generating disadvantages, systematizes individualization of affirmative remedies and further contributes to the worsening of inequality creating processes. Consequently, disabled people rather than organizing around shared cause that voices larger audience’s needs are motivated to look after addressing their individual disadvantages that are further privatized and detached from structural context with the effect of charity system incorporated into state.

Due to reduced mobility expectations that affect socialization and access to informal support mechanisms at older ages, financial concerns are voiced more frequently by respondents over 40 years old. Older respondents expect to be less active in near future and they think that a reduced activity level will also affect their socialization potential. They express concerns about being alone and unable to satisfy financial worries. The eligibility criteria for charity set by NGOs[5] also confirm the concerns of older respondents by emphasizing age as a significant factor in decision-making for charity. In view of that, financial concerns are expressed more frequently because of reduced socialization expectations and inability to access resources of informal networks at older ages.

> "The effect of my impairment becomes more obvious and restricting as I get older. Now I am 48 years old and I am staying at home more than ever. I cannot socialize as much as I want to." (Aylin, F, 48 years old).
>
> "I will be less active." (Can, M, 48 years old).
>
> "Now I am getting older, I will be more at home." (Beste, F, 42 years old).
>
> "I am planning to retire in the near future and my income level will decrease. Eventually I will be stuck at home even if I do not want to". (Deniz, M, 44 years old)

During interviews, disabled participants' experiences and expectations from state confirm the significance of redistributive remedies and governmental supports in addressing economic hardship that they frequently face. Concurrently, according to the figures of 2002 Disability Survey, 61.22% of people with disabilities expect and request monetary aid from state. Therefore, governmental supports and legislative framework regulating social policies and entitlements have a crucial role for people with disabilities in Turkey.

In order to better understand how disability is considered from state perspective and which aspects and policies are influential, it is beneficial to briefly explore disability policy in Turkey as well as social policy related legislative efforts. First of all it will not be wrong to state that disability policy in Turkey has mainly adopted a legislative driven approach without realizing an effective and ambitious implementation.

In Turkish legislation there are direct and indirect provisions to promote and protect the rights of people with disability and support their participation to life. However legislative efforts that shape public policies and institutional framework have been far from proper implementation ensuring equal opportunities and participation on par with others (Gökmen 2007, Özgökçeler & Alper, 2010). In this study, the Turkish

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[5] Annex B

disability policy's legislative driven approach that has been poorly implemented is commonly criticized by disabled respondents and expressed as a reflection of state's mentality regarding disability.

> "The extension of deadline regarding accessibility provision in Turkey directly reflects the mentality of Turkish disability policy. First there are legislative efforts to address problems, then legislative framework and laws are amended. State pretends to address the problems of disabled people however in reality nothing has been achieved. And NGOs remain silent during all this process of delaying tactics" (Can, M, 48 years old).
>
> "I do not believe that state has a disability policy in Turkey. State is even unable to enforce the law it enacted". (Beril, F, 24 years old).
>
> "State makes an effort in terms of its disability policy; however in practice nothing changes, I don't recognize any progress in my daily life. Everything rests on paper." (Utku, M, 41 years old).

According to Bowie C. L. (2005), it is important to identify how policy makers and policies consider and treat disabled people in order to capture why people with disabilities are subject to social exclusion. Respondents also support the same argument. In addition to inadequately implemented laws, respondents critically refer to mentality and discourses of state officials, policy makers and politicians as indicators of how state disability policy is shaped in Turkey. Accordingly, state officials' statements that are far from treating disabled people as equal citizens, abstract disability from social, political, economic contexts and equalize disability with impairment. From respondents' perspective, disability perception of state officials is frequently referred to provide explanation for inadequate legislative efforts that consider disabled people from charity perspective.

> "Not only society considers disabled people as destitute and useless but also state officials treat people with disabilities the same way by stating 'we hold in esteem and we treat you as we treat others, what else do you want?' This mentality legislates!!!" (Deniz, M, 44 years old)
>
> "This country witnessed a Minister of Health who stated, "Despite your impaired eyes, you are employed. What do you want more?" The point of view of state officials explains everything about disability policy in Turkey" (Ezgi, F, 33 years old).
>
> "There is a mentality that all people with disabilities should die so that we have a country free of disabled people. In Turkey, disability free country means where all disabled people are executed, not a country where all disabling barriers are eliminated" (Beste, F, 42 years old).

In Turkey, social polices related with disabled people did not occupy the agenda until the 70's when employment quotas (2% in 1971 Labor Code) as well as legislative efforts regulating disability allowances (1976) were introduced. (Yılmaz, 2010). Disability and old age pensions despite being considered as a milestone and the most important piece of legislation with its rights based orientation for the first time, has remained very limited due to its conditional character and strict categorical eligibility approach. Accordingly, applicants are expected to satisfy a set of criteria that involves means test, being out of social security system and absence of close relatives to look after. As can be seen from its conditional requirements, the legislation regulating Disability and Old Age Pensions is far from satisfying categorical universality for disabled people. Instead disability allowance recipients are expected to prove destituteness reminding “deserving poor” of the past. Moreover, “absence of close relatives to take care of” as an eligibility criterion for disability allowance, is a significant reflection of how family is an important welfare provider within Turkish welfare system and how the presence of family becomes a source of restriction for disability related entitlements.

As can be understood from above mentioned framework, in Turkey it is not possible to combine governmental supports such as disability and home care allowances and other income generating activities. However as also voiced by most of the respondents, disabled people frequently experience extra costs associated with disability, especially related with health expenses, that neither disability allowances nor their income is solitarily enough to afford incurred expenses.

> “I save money and plan my budget by remembering that there is a possibility that my orthesis may get broken one day. So I need to save extra money for that. Because I am alone.” (Utku, M, 41 years old).
>
> “In addition to my pension, I work as a trainer to have additional income” (Selim, M, 50 years old).
>
> “If everyone earns 2 units, I need to earn 4 units so that I can afford the expenses related with disability” (Deniz, M, 44 years old).
>
> “My husband is also a disabled person and life is very hard for us. Even buying bread is very costly for us because we need to go by car to buy bread. It is same for everything. Life is very costly for disabled people” (Aylin, F, 48 years old)
>
> “The state’s disability policy is a huge “zero”. State provides social assistance schemes as home care allowances, disability allowances but you need to starve or almost die to be eligible for entitlements. Decent income is a dream for disabled people” (Beste, F, 42 years old).

The strict conditionality affects people with disabilities to obtain decent level of income responding to realities in their life. Consequently, welfare systems through their provisions and social policy instruments become sources of exclusion for disabled people. This study shows that the exclusionary processes experienced by disabled people are closely related with legislative efforts unable to satisfy categorical universality for disability.

> "There are very strange criteria regarding disability policy. It is for sure that officials cannot evaluate properly. As disabled people we have rights but they are on paper. You cannot enjoy privileges arising from disability such as tax exemption if your income level is high". (Mehmet, M, 38 years old).

During the 2000's EU accession partnership together with ratification of UNCRPD have been important factors in developing disability rights and policies in Turkey. In 2005 the first comprehensive legal instrument regarding disability "Law on Disabled People" is adopted. The Law on Disabled People, on one hand has extended disability benefit levels and introduced new forms of social policy instruments such as home care allowances, on the other hand amended the system evaluating disability by adopting ICF, which is affected from the paradigm shift of welfare to workfare. Consequently, the amendment excluded a great portion of disabled people population who has been previously entitled disability allowances. In other words, despite the introduction of new forms of social policy instruments and increase in benefit levels as promising trends, financial and institutional burden of disabled people on the state is addressed via amending legislative categorization of disability. In a sense what is repaired with the law is ruined with amendment of other legislative instruments as by-laws and communiqués for the sake of state interest. State's categorization of disability and stricter means testing appear as critical features in this hypocritical process.

> "State on one hand entitles rights and privileges to disabled people but on the other hand it makes an effort to restrict those rights" (Can, M, 48 years old).

In addition to amendments about legislative categorization of disability, efforts to define deserving cases by differentiating disabled people among themselves and targeting who "needs" more on the grounds of strict means testing are also sources of exclusionary processes for people with disabilities. Eligibility criteria for entitlements like home care allowances as well as disability pensions have their share from political economy transformations and necessitated a stricter means testing through a household scale calculation method. The new method extends the income analysis from individual to household level. Accordingly, the beneficiary is expected to satisfy a threshold value through proving that average monthly income per person in the household is no more than 2/3 of net minimum wage.

In a country where even the amount of minimum wage is very contestable and appears as a prominent election promise, supporting disabled people who frequently incur extra costs associated with disability, only when they have such a low income level as 2/3 of net minimum wage, means that unless disabled people and their families are destitute, they are doomed to informal support mechanisms either it be informal state support, state charity or charity of NGOs. Hence, in Turkey to have an income level even slightly above minimum income threshold appears as a punishment for disabled people and disqualifies them from additional sources for decent income. In other words, they are left alone to manage disability related needs.

> "I wish to afford a personal caregiver. I have an income level more than minimum income, for that reason I am not eligible for home care allowances. But my income level is not sufficient either to hire a caregiver. I am in limbo" (Deniz, M, 44 years old).
>
> "Minimum income is very low in Turkey. A disabled person needs more than that amount of money because when it is possible for everyone to take a bus, a disabled person has to take a cab especially in winter period. Life is more costly for disabled people" (Aslı, F, 41 years old).
>
> "Policies and entitlements should be determined by taking realities of life and realistic numbers into account". (Aslı, F, 41 years old).

In order to be eligible for monthly disability allowances, satisfaction of household scale income analysis has further exacerbated already difficult financial situation of people with disabilities. This legislative amendment serving to restrict categorical policies confirms Elwan's (1999) argument that "disabled people are usually considered to be the responsibility of their families." The rationale behind the change in unit of income analysis expressed as "welfare is a conception that is shared among household scale" is a reflection of treating family as a central welfare provider and disabled people as dependent family members instead of independent individuals. Consequently, inability to satisfy household scale income analysis results in exclusion of considerable portion of disabled people who are still in need of governmental supports.

> “There are people whose disability allowances are cut down because their brothers or relatives start working. According to the state, if someone in the family starts working, everything will be solved and every need will be addressed” (Deniz, M, 44 years old).

Since the economic and institutional burden of disabled people on the state is restricted through legislative efforts and through transferring state’s liabilities to other informal actors to some extent, disabled people ultimately become more vulnerable and dependent on others means of support mechanisms as charities. According to Küçükaslan (2013), from state perspective people with disabilities are the ones expected to be grateful, stuck in never ending procedures, subjects of charity and disregarded individuals who are social policy propaganda subjects. Below quoted argument also describes well the situation in Turkey where the state still considers the rights of people with disabilities from a perspective of charity that reminds “cap in hand”.

> “People not covered by social security can access more resources, opportunities and support via charities than those under social security umbrella. Therefore charity becomes a more beneficial substitute than entitlements provided by government” (Ezgi, F, 33 years old).

As Abrams and Christian (2007) assert legislating for the selective treatment of different groups or individuals has an effect on inclusion and exclusion at institutional level. In line with this statement, this study also confirms the significance of legislative efforts involving selective and discriminative treatment among disabled people as a critical factor behind exclusionary processes. The best example regarding differential assessment among disabled people is the Communiqué on Healthcare Implementation (Sağlık Uygulama Tebliği-SUT). The Communiqué herein after referred to as SUT is a unified guide published annually which covers the rules and regulations for health benefits package, treatment expenses as well as participant share for assistive devices. As previously discussed healthcare expenses as well as assistive device needs have significant place in the lives of people with orthopedic disabilities and in this study during interviews respondents frequently referred to the significance of healthcare related expenses. Therefore legislative efforts regulating healthcare expenses such as SUT are highly important for disabled people.

Despite being a significant piece of legislation, SUT has provisions directly discriminating among disabled people based on how they have become disabled. It has different practices setting some disabled people above other disabled people. According to article 1.8.5 of the Communiqué, while terror-stricken, veterans and earthquake victims are exempted from participation share in some health expenses as assistive device and medical supplies provisions, other people who have congenital or acquired impairments are obliged to pay participant share for the same processes. What is more to the point is that SUT even differentiates between earthquake victims of different years by specifically referring to earthquakes happened in 2011 and exclude victims of earthquakes happened earlier. Only people with impairment because of 2011 earthquakes are exempted from paying participation share. These kind of discriminative practices privileging some disabled people over other disabled people exclude a great portion of individuals with disabilities and leave them alone with their health problems. Are some disabled people more equal than others? is commonly asked by respondents due to discriminative nature of the Communiqué on Health Implementation.

> "We are all disabled. State should not distinguish between its veteran disabled citizens and other disabled citizens" (Beril, F, 24 years old).
>
> "There is discrimination in SUT, but I feel adoptively uncomfortable to criticize privileges granted to veterans and terror stricken. However, state should not discriminate among its disabled citizens" (Utku, M, 41 years old).
>
> "It is not fair to differentiate one disabled person from other disabled person. State with its policies implicitly says that "veterans or terror-stricken are my disabled citizens" and "you are not". (Aslı, F, 41 years old).

Within the scope of SUT, initially disabled people are expected to acquire assistive devices and medical supplies responding to their medical reports through their own means and reimbursement are only made after the submission of necessary documents to social security offices. Most of the time reimbursement occurs within 50-60 days after initial provision of devices. Therefore long waiting periods for reimbursement makes it impossible for disabled people who lack financial competence to afford and acquire necessary assistive devices. This kind of disincentives makes disabled people to disclaim their rights and results in failing to satisfy their needs. In this study, respondents who are able to afford the extra costs associated with disability define themselves lucky which mirrors well the exclusionary processes in Turkey.

> "I belong in a lucky minority because I can afford the expenses attached to disability. Entitlements and aids provided by state do not respond to meet my needs and the bureaucratic procedures are so long and tiring that you give up at some point. Eventually you try to find other means to satisfy your needs. In a way, there are legal arrangements but you have to be stubborn enough to be entitled and enjoy your rights" (Ezgi, F, 33 years old).
>
> "I satisfy my assistive device needs through my own means. I am not happy either to pay at least 1000tl a month for my medical expenses. But I have no choice. Because once I used the wheelchair given by state and it made me feel more disabled than ever" (Aslı, F, 41 years old).
>
> "People with disabilities experience difficulties regarding assistive device provision. I know this bureaucratic process therefore I pay the expenses of my wheelchair by myself. But disabled people unable to afford such expenses are doomed to charity campaigns. If people with disabilities satisfied their assistive device needs as their citizenship rights, resources and time spent for charity campaigns could be used more effectively" (Ezgi, F, 33 years old).

In addition to its discriminative provisions, the Communiqué on Healthcare Implementation with its inelastic characteristics involving long lasting reimbursement periods, inadequate pricing policy for health expenses, "one size fits for all" understanding unable to respond personal needs and strong emphasis on medical assessment overlooking social and environmental aspects, is an exemplary piece of legislation protecting state's interest at the expense of human centered policies.

> "The assistive devices that I need are out of the scope of legislation and the ones covered by legislation do not meet my needs. I try to meet my medical and assistive device needs by myself" (Deniz, M, 44 years old).
>
> "State should appropriately undertake its responsibilities regarding its disabled citizens. But usually state pretends to undertake rather than fully undertaking its responsibilities. For instance, it is not possible to use the wheelchairs financed by state if you are an active individual. That is usually what state provides…" (Beril, F, 24 years old)
>
> "I applied to receive healthcare benefit in order to have a wheelchair. They gave me 250 TL three years ago. I asked them what could I buy with this amount of money. Officials told me that there were hospital type wheelchairs and I could use these. If I didn't want a hospital type wheelchair, then I was supposed to go and apply to disability NGOs, they could help me." (Beste, F, 42 years old).
>
> "The process of assistive device provision is very long and bureaucratic. First you need to get a medical report. Then you need to go to medical products dealer for proper measurements. In the end if the orthesis that you ordered does not meet your needs, you have to start all over. But this time you are all alone because you wasted your chance and this time you need to pay all expenses of readjustment of orthesis by yourself."(Aylin, F, 48 years old)

The Communiqué with its discriminative provisions clearly create exclusion by giving a group of disabled people privileged position over others. Disabled people who are not able to afford health related expenses as well as assistive device provision, are at a disadvantaged position both in terms of access to health as well as access to social, economic and political life due to the multidimensional nature of exclusion. Additionally, legislative framework privileging some disabled people over others, destine those unable to afford expenses by themselves to informal support mechanisms as charities.

Regardless of gender and age variables, there is a consensus among respondents that if the state and its social policy instruments properly address the needs of its disabled citizens, there will not be any charity activities claiming to satisfy needs of disabled people. Therefore the common agreement among respondents centers on significance of inadequate state policy in determining the complex relationship between disability, exclusion and charity.

> "If unnecessary state expenditures are transferred to meet the needs of disabled people, I believe that there will not be a need for charity" (Aylin, F, 48 years old).
>
> "When state's disability policy fails, NGOs become the king. There is a saying "in the land of the blind, the one-eyed man is king". This is true for disability related NGOs" (Beste, F, 42 years old).
>
> "Disabled people are subjects of both social and political agitation in Turkey" (Ali, M, 30 years old)
>
> "Disability is a serious issue. Appropriate and comprehensive solutions can be achieved through appropriate political stance. Perfunctory policies adopting charitable attitude cannot address disabled people's problems" (Aslı, F, 41 years old).
>
> "According to me there won't be any need for charity when people with disabilities' access to education, employment and social life are ensured on equal par with others" (Sevgi, F, 45 years old)

In the context of disability, Turkish welfare system adopts a strict category based social protection that requires proof of extreme poverty and medical evaluation of disability to limit target group and to test who are work-able and who are eligible for governmental supports. According to respondents, disabled people unable to satisfy these criteria are left alone with risks and injustices and become vulnerable in the face of exclusionary processes.

To sum up, respondents critically refer to disability and disability related policies in Turkey and state that they have not been considered as a political issue at all. Within the sample of this thesis, political economy, insufficient governmental supports adopting charitable view, informalized redistributive remedies, legislative framework involving discriminative provisions among disabled people are voiced as the most crucial structural factors behind the complex interplay among disability, exclusionary processes and the role of charity.

4.1.2 Medicalization of Disability

In this study, medicalization tendency regarding disability is found to be one of the most influential structural factors behind exclusionary processes experienced by disabled people. As briefly mentioned in the previous section, disability and disability related policies in Turkey are considered as a medical issue that is mainly addressed by limited redistributive remedies unable to satisfy categorical universality. Accordingly medical reports assessing the extent of disability appears as the first and most important step from both state perspective and NGO's perspective in order to be "legally" considered as disabled. Those who are above an extent of disability threshold of 40% are eligible to enjoy rights and exemptions attached to disability and defined as disabled in legal terms.

Prior to enjoying rights and privileges associated with disability, individuals are expected to prove their medical condition with a medical report. In a sense without a medical report, disabled people are without ID cards in Turkey. In line with Stone's (1984) views, in Turkey, medical certification and evaluation is one of the most important mechanisms to further categorize disabled people as an administrative category. Respondents critically referred to the significance of medical reports in denial or access to equal opportunities in the lives of disabled people. Additionally, in this study it is revealed that people with disabilities experience very challenging processes in order to prove that they are disabled in legal terms. Many of them are facing violations related with disability reports and never enjoy their rights fully as defined in the law.

> "Medical Report is a serious piece of paper because it affects a range of opportunities like employment, assistive equipment needs, home care allowances…etc. To enjoy rights and privileges attached to disability, medical report is a must. But there is not a consistency regarding medical reports. Each hospital and doctor has a different evaluation. If a doctor had a fight with his wife the day before, his emotional state of mind also influences the outcome of medical report." (Demir, M, 24 years old).

> "I really do not know what medical report evaluates? Medical reports for sure occupy a significant place in the lives of disabled people because it is the first step to prove whether you are disabled or not. To what extent a disabled individual enjoy the rights and privileges granted by state depends very much on what does his/her medical report state. Besides,

> depending on the reason of application for medical report, either you are considered more severely disabled or less. There is no objectivity at all.” (Ezgi, F, 33 years old)

The medical assessment of disability in Turkey dates back to the late 60’s when Turkish Impairment Scale is developed to evaluate disability in medical terms. While during the 60’s and the 70’s disability rights movement were interested in equalizing opportunities for disabled people, during same period of time in Turkey assessing disability in medical terms were the main agenda item. In 1998, the By-Law on Medical Reports Issued to People with Disabilities *(Özürlülere Verilecek Sağlık Kurulu Raporları Hakkında Yönetmelik)* is published with the aim of assessing disability and standardizing loss of working capacity assessment. Whereas in 2006, the By-Law has been renamed as “the By- Law on Criterion and Classification of Disability and Medical Reports Issued to People with Disabilities” and disability assessment system has been amended by taking ICF as its basis where impairment and capacity limitations are differentiated from each other.

The change in disability assessment system influenced a great portion of disabled people who previously had a medical report with an extent of disability above 40% by re-evaluating them and lowering previously issued extents of disability below the threshold value. Consequently, the ones who have been previously enjoying rights and privileges attached to disability have become ineligible (Yentürk &Yılmaz 2012, Yılmaz, 2011).

In Turkey, dominance of medical view in defining “who is disabled and to what extent” emphasizes functional limitations and underestimates social aspects and environmental factors. The strong medical stress obscuring complex interplay between social, economic, institutional and political contexts eventually results in adoption of a segregated vision that treats disability a standalone issue. Accordingly, doctors and medical specialists have significant role in evaluating potential performance as well as the effect of impairment that adopts non-disabled people’s standpoint. The medical evaluation taking “normality” as a reference is influential in decision-making about disabled people. When the assessment of medical specialists focuses on functional limitations, it becomes necessary for disabled people to put endless efforts in proving themselves regarding their abilities, employability, medical needs, social assistance needs etc.

> "All through my life, I was expected to prove people that I am able to do some activities via medical reports. While for non-disabled people it is more than enough to have a diploma to pursue their dreams, we- as disabled people- are always expected to prove our abilities through medical reports." (Sevgi, F, 45 years old)
>
> "The ideology of normality is very dominant in Turkey. It is ridiculous to prove each time that I am disabled through medical reports." (Aslı, F, 41 years old).
>
> "I am sick and tired of experiencing discrimination, inequalities, injustices as well as questioning eyes expecting me to prove my abilities each and every time." (Sevgi, F, 45 years old)

According to the By- Law on Criterion and Classification of Disability and Medical Reports Issued to People with Disabilities the committee examining disability reports is solely consisting of health specialists with medical background. They are expected to evaluate broad range of issues that are usually out of their expertise such as decision making about who can do what sort of jobs, who are eligible to have a driving license, who needs what sort of assistive equipments etc. Although medical specialists are not experiencing impairment personally, their decisions and their perspective of what is best for disabled people directly affect those who experience impairment everyday in their lives. Especially decisions about disabled person's field and level of employability have direct influence on potential material deprivation and degree of dependency on informal mechanisms.

Medical reports and medicalization tendency are not only significant for state perspective but also for disability related NGOs and informal support mechanisms as charity activities. Without exception, each interviewed NGO gave reference to medical reports as a significant criterion[6] for charity eligibility. Moreover NGOs employ medical evaluation through their science boards in deciding who is eligible for charity and what sort of assistive equipments suit best for the needs of disabled applicant. Science boards of NGOs dominantly consisting of medical specialists decide on behalf of disabled people who personally experience impairment everyday and act as critical player in providing or denying opportunities. It is for sure that a medical specialist cannot be competent or knowledgeable about all areas of life. But current system forces them to decide about everything related with people with disabilities. Therefore medical specialist's decision and medical gaze directly have

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huge impact on whether increasing or reducing capabilities of people with disabilities.

In line with Drake’s (2001) argument that medical evaluation is one of the key instruments to ease burden on welfare states through deciding who is eligible for entitlements or not; this study reveals the significant role played by medical reports as a control mechanism. As respondents share their experiences, depending on the reason of application for medical report, assessment about the extent of disability varies to a great extent, which eventually affects enjoyment of rights and exemptions. Although the By-Law aims to set out standardization of assessment and processes, outcomes experienced by disabled respondents rebut and contradict with what is originally aimed. In the 2006 version of the By-Law, the exception revealed itself regarding tax reductions by setting medical reports for tax deductions out of the scope of the By-Law, which show state’s understanding prioritizing economic rationale above all. Although in 2010 provision leaving tax reductions out of the scope of the By-Law has been amended, medical reports issued for invalidity pensions for those under contributory social security system are still left out of the scope of standardized disability assessment. Respondents commonly voiced that unlike the initial intention of standardized disability assessment, they experience challenging processes and different outcomes that have direct reflections on their lives.

> “Depending on why you need the medical report, officials/experts issue different medical reports. I think that extent of disability is determined based on the reason of application for medical report” (Elif, F, 26 years old)

> “To what extent you are considered disabled depends on and changes with why you apply for a medical report. For instance, one of my friends who wanted to retire applied for medical report to prove his disability condition and enjoy early retirement opportunity. However since the reason to request medical report is “retirement”, suddenly it turns out that he is not disabled enough. I still do not know the logic behind medical reports.” (Ali, M, 30 years old)

> “Medical reports issuing different extents of disability for the same disabled person with static medical condition is a reflection of state hypocrisy. Although the procedure to classify and evaluate disability is standard, there are different implementations and consequently different results depending on the purpose of medical report. For instance, a disabled person gets a higher extent of disability if he wishes to have a medical report for income tax reduction but if the purpose is to acquire a car with tax exemption then it is almost impossible to have a medical report with a high extent of disability. Therefore under standard procedures, state is hypocritical because of issuing medical reports with different extents of disability. The extent of disability is changing from one report to another for a person with disability with a static health condition.” (Sevgi, F, 45 years old)

> "I do not think that medical reports properly assess the disability status of applicants. I had several medical reports stating different extents of disability. I was personally very surprised with different reports about my disability status." (Beril, F, 24 years old).

> "After the legislative amendment regulating medical reports, I personally asked from doctors to issue a medical report with lower extent of disability for me. Because in my field of work, which is preschool education, it is not possible to be employed with high extents of disability". (Aslı, F, 41 years old)

In line with above-mentioned features, disabled participants point to the fact that medical reports function as a control mechanism in order to protect state's interest. Both different extents of disability analysis depending on purpose of medical report application and amendments in disability assessment system result in restrictions for disabled people. In a sense, medical reports serve as a gatekeeper to manipulate and restrict rights and exemptions defined by law in Turkey. The role and significance of medical assessment and the way it is translated and reflected in policies are important determinants behind exclusionary processes associated with charity.

> "There is no scientific logic behind medical reports." (Mehmet, M, 38 years old).

> "Medical reports appear as a mean to withdraw rights and entitlements available to disabled people by laws". (Can, M, 48 years old)

> "You are disabled as long as the state wants to consider you disabled. Medical reports and the way disability is assessed are crucial factors in this decision." (Sevgi, F, 45 years old)

Medical dominance and medical reports' main emphasis on the effects of impairments further underlines and reinforces pre-existing dichotomy about disability and ability. The medical standpoint focusing on limitations equalizes impaired body with disability and forces disabled people to either prove their abilities or deficiencies through medical reports. This tendency not only restricts opportunities within legal framework but also affects how disability is perceived by society as well as by NGOs as active players in the context of disability. Consequently, the medicalization and privatization of disability have reflections on the activities of disability related NGOs and how they function, what sort of role they play in exclusionary processes associated with charity.

4.1.3 The role of NGOs

As discussed in previous sections charity system incorporated into state institutions (talep takip sistemi) make NGOs become critical players in structural context. In this study one of the most influential structural factors behind socio-cultural exclusionary processes and the role of charity in these processes are determined as disability related NGOs and their activities. In order to better understand the relationship among NGOs, the state and disabled people as well as the disability movement in Turkey, it is beneficial to focus on activities, discourses and profile of interviewed NGOs[7] and how disabled people perceive NGOs in the field of disability.

In Turkey where lately developed welfare understanding is unable to satisfy categorical universality for disabled people, NGOs evidently play a crucial role in shaping how disabled people experience disability and exclusionary processes associated with disability. Moreover, from state's perspective, disability NGOs are considered to have expertise about disability that state does not have. Accordingly, this understanding results in confusion about how liabilities and responsibilities are shared between different parties such as state and NGOs while addressing disability as well as policy making concerning disability (Buğra, 2006; Yılmaz, 2010; Bezmez&Yardımcı, 2010).

> "Inaction of state or polices far from addressing actual experience lay a serious responsibility on NGOs. Here, the responsibility in question is about activating state to realize its duties and liabilities. But there is a serious problem arising from confusing responsibilities with liabilities. NGOs instead of reminding state to meet its liabilities and fulfill its obligations, undertake state's liabilities" (Buğra, 2006).

This study reveals that confusion about roles and responsibilities between NGOs and state affect how NGOs set priorities and manage their activities as well as how people with disabilities define their relationship with respect to disability NGOs. The experience and statements of disabled respondents and NGOs' representatives clearly underlines the confusion about roles and responsibilities between the state and NGOs in the field of disability.

> "In the absence of the state, it is very normal that NGOs exploit disability and agitate to raise funds. Besides, there are lots of disabled people unaware of their rights, so it is easy to manipulate them. NGOs instead of lobbying for improving state's disability policy and advocating disability rights prefer profiting from insufficient state policies". (Ali, M, 30 years old).
>
> "NGOs steal the role of the state. Their main responsibility should be to defend and protect the rights of disabled people, instead NGOs try to act like state and undertake state's responsibilities. There is confusion of roles". (Beril, F, 24 years old).

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In this study, when NGO representatives are asked to elaborate on the role, scope, priorities and activities of the NGOs they represent, the mostly referred issues appear as “assistance”, “help”, “prevention of disability”, “protection”, “awareness-raising”, “guidance” and “equal participation”. Unlike grand narratives involving “advocating equality for all” and “rights based approach to disability” that are frequently voiced during NGO interviews and through NGOs’ web sites or social media accounts, “empowerment” of disabled individuals and political mobilization questioning conventional approaches are barely heard from NGO representatives. Instead, the main priority of interviewed NGOs centers on fund raising, charity and literally “helping” disabled individuals in kind or in cash in order to address their needs or problems.

In Turkey, the role of disability NGOs in undertaking the responsibilities of the state, filling the gap of insufficient policies and acting as help centers and assistive device intermediaries in close relation with the state is commonly criticized by respondents. They attract attention to how easy it is to establish an NGO and how frequent it is for NGOs to quit advocating rights and become help centers soon after their establishment. Moreover, according to disabled people, NGOs are after their survival, which has significant effect on the scope of their activities, priorities as well as their relationship with disabled individuals.

> “It is the easiest thing to establish an NGO in Turkey. If 7 people gather together, they can establish an NGO. If three NGOs gather together, they can from a federation and when federations unite, they are able to form confederations…etc. NGOs have the leading role in charity campaigns” (Utku, M, 41 years old)
>
> “Once upon a time, my friends and I established a disability related NGO. However soon after the establishment, our NGO became a medium of fund raising. We were almost asking money from each and every people we met. It was not my intention at all in the first instance. My first intention was to provide a civil initiative where people can socialize. I was very disappointed and I quitted. It was a total disappointment for me”. (Aylin, F, 48 years old)
>
> “Still fund raising and charity campaigns are very dominant activities of disability related NGOs. When a disabled person hears the word NGO, he or she immediately thinks, how can this NGO help me?” (Aylin, F, 48 years old)
>
> “NGOs have great influence on the degree of social acceptance and support behind charity campaigns such as “blue lid campaign”. When NGOs realize that such campaigns are profitable, they emphasize more and more”. (Ahmet, M, 35 years old)

Both from the state and NGOs' side as well as disabled people's perspective, the relationship between NGOs and disabled people is dominantly defined through "need" and "satisfaction of personal needs". NGOs are seen as organizations that should satisfy the needs of their members and those in need. Not only NGOs reinforce the above-stated image by marketing themselves as help centers but also state institutions and municipalities through their individualized requests from NGOs, promote dominance of charity within NGO activities.

The views and experiences of NGOs also confirm the significance of "need" in building a relationship between disabled people and NGOs. "As a disabled individual, if you do not need, you will not come to us. But if you come cap in hand and apply timidly to our NGO, it means that you are definitely in need". (NGO 5) From NGOs' standpoint, it seems usual to have a "needs based interaction" at the center of the relationship between NGOs and disabled individuals.

From the perspective of people with disabilities, again the "needs" of disabled individuals appear as an important feature to engage in NGO activities. For instance, Beril (F, 24 years old) states that she is not a member of any disability related NGOs because she did not "need" any NGO. Those who are able to meet their needs and afford disability related expenses by their own avoid becoming members or avoid participating in NGO activities. "I do not feel belongingness to any of the disability related NGOs" said Mehmet (M, 38 years old) who belongs to lucky minority able to meet their needs by themselves.

Although especially younger respondents state that they expect NGOs to advocate a rights based approach to disability and act as a pressure group, at the same time they deeply internalize perceiving NGOs as "charity kingdoms" and instead of participating and changing what is wrong in NGOs; they prefer to stay away from disability NGOs.

> "I am not interested in disability related NGOs at all. They are unnecessary and they do nothing but harm. They gather disabled people together and pile on the agony". (Elif, F, 26 years old).

> “Marginalization and discrimination that I am experiencing is rooted in NGO activities and inefficient state policies. NGOs are managed by non-disabled people who think that all people are potential candidates of disability”. (Ahmet, M, 35 years old)
>
> “If NGOs were influential, they could have become a pressure group, lobby and press for permanent and transformative change. TBMM cannot and will not legislate unless there is proper guidance provided by people who personally experience the difficulties. But this is not the case in Turkey”. (Mehmet, M, 38 years old).
>
> “Instead of standing up for disabled people’s rights, NGOs line their own pockets”. (Elif, F, 26 years old).

Above explained situation mirrors the dominance of “organizations for” (Shakespeare, 2000, Drake, 1997) in which the priorities and agenda are set by non-disabled hegemony. From respondents’ point of view, dominance of “organizations for” in the context of disability worsens social exclusion experiences by overshadowing institutional deficiencies.

Within the sample of this study, statements of interviewed NGOs reveal that NGO activities mainly prioritize fund raising efforts for health operations of people with orthopedic disabilities and charity campaigns promoting assistive equipments as the most important problem of people with disabilities. Instead of pursuing an ambitious approach questioning the underlying causes of multiple forms of exclusionary processes, “individualized remedies” for “individualized problems” by providing one time, visible and immediate solutions as assistive equipments provision are presented as panacea for all problems. However, NGOs are commonly criticized by disabled respondents because of prioritizing charity activities as the first and only concern in their agenda.

When disabled respondents are asked to share their opinions about NGOs, they frequently referred to charity campaigns and NGOs interchangeably. Just this tendency alone is a good reflection of how respondents equalize charity with NGOs and vice versa in Turkey. In this study, disabled people commonly expressed discontent about the role of NGOs in depoliticizing disability and degrading multidimensional injustices to only material deprivation. From respondents’ perspective, the efforts of NGOs contribute to legitimate unmet liabilities of the state and enhance perceptional misunderstanding about disability. The activities of NGOs, through degrading disability to impairment as well as degrading multidimensional injustices to material deprivation worsen exclusionary patterns.

> "Disability related NGOs have negative contribution than positive outcomes. NGOs make subordination of disabled people superficial. All the problems are reduced to monetary and assistive device needs." (Ezgi, F, 33 years old).
>
> "People think that the only need of people with disabilities is wheelchairs". (Beste, F, 42 years old)
>
> "Wheelchair is a symbol; it is the easiest thing to do. A disabled person has multidimensional needs but assistive device need is the most visible and easiest one". (Deniz, M, 44 years old)
>
> "NGOs have great influence on the degree of social acceptance and support behind charity campaigns such as blue lid campaign. When NGOs realize that such campaigns are profitable, they emphasize more and more. The real and significant problem is that even children contributed to the campaign and collected blue lids. Children's perception about disabled people is shaped by such a wrong campaign, can you imagine? These charity campaigns not only affect today but also destroy tomorrow. The next 30 years are affected with the blue lid campaign". (Ahmet, M, 35 years old)
>
> "I criticize NGOs related with disability because they categorize people as disabled and non disabled. Instead there should be sub commissions or committees for disability in each NGO. Otherwise "blind leading the blind" approach will persist". (Sevgi, F, 45 years old)
>
> "NGOs help people to ease their conscience through donations. They enhance the idea that if people donate to raise funds for wheelchairs, sticks or other devices, every problem of disabled people will be solved. Whereas the most important problems of people with disabilities involve education and access to employment". (Sevgi, F, 45 years old)
>
> "Monetary aid is the simplest and easiest one. It is believed that as a disabled person you certainly need something and you certainly do not have enough money to satisfy that need. Being disabled is peculiar to low-income level, material deprivation, low socio-economic status etc." (Sevgi, F, 45 years old)

The sources of financing and how NGOs generate necessary funds to operate are crucial determinants in NGO activities and its relationship with society, state institutions and disabled people. During interviews, while NGO representatives elaborate on financing of NGO activities and operations, fund raising through "donations" appear as the main source of revenues. Although income through sales of handcraft, rental income, and revenues from social activities are also expressed as other means of financing, the most dominant and important financial contribution comes from donations. Except NGO5, none of the interviewed NGOs gave reference to membership fees as a source of finance. The limited or lack of financial contribution from members and the share of donations in financing raise concerns about NGOs' economic dependency, transparency and patronage relations between different parties.

In Turkey although the state does not have direct contributions to NGOs in terms of financing, the decision to grant “association for the public weal” *(kamu yararına dernek)* as well as “authorized association to fund raise without permission of related state authority” *(izinsiz yardım toplama yetkisine sahip kuruluş)* rest with the state through the medium of the decree of council of ministers. Since donations and fund raising activities have significant share in financing NGOS, decisions on granting privileged status are very effective in defining the patronage relationship between NGOs and the state. In a sense a sword of Damocles hanging over the NGOs describes best the relationship between NGOs and the state. This mechanism functions better to control NGOs and make them act as satellites of state institutions through satisfying their part in charity based social policy system.

Respondents also complain about the patronage relation limiting disability activism as well as lack of criticism against state policies and institutional capacity.

> “For me, disability related NGOs should not be dependent on government and its funds. But currently NGOs are dependent on government. Executive board members instead of defending disability rights and adopting rights based approach, pursue a political career and wish to become a member of parliament one day. They look after their personal interest. Disability related NGOs are in close relationship with political parties and act like the backside of these parties. Their main aim is to find out what can be done to get more votes in the elections for parties they are in touch”. (Aslı, F, 41 years old)

Currently, there are 20 associations or foundations that are granted authorized status to raise funds without permission of related state authority and one of them is among the interviewed NGOs in this study. The reluctance or hesitation of NGOs in criticizing state’s disability policy reminds the sword of Damocles hanging over them. This study confirms the statements of Bezmez &Yardımcı (2010, p.606); “a kind of NGO-state relationship, where the former remains under the protection of the latter aiming to benefit from its charity in return”. Instead of mobilizing and promoting disability as a political issue, remaining silent and avoiding activism give better results either for preserving already granted privileged status or for securing one. Same rule also applies to micro level relations. Similar to state’s passive engagement that results in better control mechanism, relationship between NGOs and disabled individuals also aims to secure a bond of gratitude. Respondents especially in the old age sample state that the more an individual is silent and support NGO activities the better he/she can benefit from what NGOs offer.

> “NGOs look after their own survival and serve to the privileged minority close to executive board”. (Ezgi, F, 33 years old).
>
> “NGOs abuse the good intentions of people and society. Each time NGOs select same names and people either for a summer camp or for provision of wheelchairs. In the end a beggar society is enhanced”. (Can, M, 48 years old).
>
> “NGOs are evil minded. They do not use grants properly”. (Ahmet, M, 35 years old)
>
> “After the establishment of a disability NGO, in a short while executive committee usually decides to establish commercial enterprise to finance its activities and most often the main objective becomes their survival, not the actual problems of people with disabilities” (Ezgi, F, 33 years old)
>
> “NGOs pretend to help disabled people, in reality they serve to their self-interest. Their activities damage respectability of people with disabilities. While helping others, in reality they look after their own interest. NGOs help people who are close to them; they do not help real needy individuals”. (Selim, M, 50 years old)

In this study, it is found out that there is a chicken and egg situation with regard to the dominance of charity, medicalization of disability in NGO activities and limited involvement of disabled individuals in disability movement. From disabled people’s perspective NGOs, instead of promoting activism questioning disabling barriers and transform conventional attitudes, adopt medicalization and privatization of disability, which work better to secure more support and donations from society. This preference distances people with disabilities from disability NGOs. The more disabled individuals are distant from NGOs the less able they are in directing and influencing NGOs according to their priorities.

Both NGO interviews as well as disabled people’s experience reveal that in Turkey disability NGOs reproduce and reinforce conventional attitudes towards disabled people and they are weak in mobilizing and promoting disability as a political issue. There is still heavy dominance of medical model of disability from NGOs’ perspective as well.

4.2 The Cultural Factors Determining the Significance of Charity Dominance in Disability

4.2.1 Social Perception and Cultural Representation of Disabled People in the Society

The complex interplay between social circumstances and the role of society are significant features in determining how disabled people experience disability, exclusionary processes and the degree of charitable dominance in disability. The way disability is perceived in the society is important not only because it has direct impact on the development of legislative framework, policies, programs and their outcomes but also on cultural representation of disability and to what extent disabled people can convert social competences to opportunities. Accordingly, how disability is socially (re)-constructed, perceived and interpreted affect real life experiences, capabilities and provide valuable information regarding dynamic relationship between disability, charity and social exclusion experiences of individuals.

In this study from respondents' perspective, "disability" signifies an important indicator to categorize people and label them under two mutually exclusive groups as disabled and non-disabled. The society through equalizing disability to impairment or biological inferiority associates and constrains people with disabilities with particular social roles which reflect societal expectations about how disabled people should live, what they need etc. In a sense, disability appears as a marker that encompasses everything.

> "The only specification that defines me is my impairment. I am just a disabled person for society, even if I can split the atom or I have a brain similar to Einstein's it does not matter, what defines me is my impairment. I am just a disabled person for society". (Ahmet, M, 35 years old)
>
> "I was working for TAI and considering changing my job. At that time Siemens had a vacant job and I applied to that position. In the meantime, I was very experienced about Siemens because my position at TAI involved a joint project with Siemens during which I worked as a contract expert and I was preparing contracts of Siemens. The position that I applied was again related with contracts. After my interview at Siemens, they offered me a position at information desk, which does not require any qualification at all. So disability encompasses everything. Once you are disabled, you are nothing more". (Sevgi, F, 45 years old)
>
> "According to societal perception, we, as disabled people do not look beautiful because we have wheelchairs, walking sticks, prosthesis… etc. " (Can, M, 48 years old)

> “They already have stereotypes regarding “how I should live”, “what can I do and what I cannot”. (Ahmet, M, 35 years old)
>
> “The process leading to social acceptance is very painful. Without exception in every new environment whether it be a work place or a social, educational area, I am without identity until I make people know and accept me”. (Sevgi, F, 45 years old)

Social exclusion experiences and the role of charity in the lives of disabled individuals are closely related with presenting and constraining them within specific roles. Without exception each respondent regardless of gender, belonging to younger or older age sample, states that disabled people are seen as destitute, useless, unnecessary, disrespectful, pitiful, incomplete and dependent individuals by society. Since people with disabilities are not expected to do or accomplish usual things as non-disabled people do, from societal perspective they “need help” to manage their life and charity seems a useful way to do it. Recognition problems lead society to adopt charitable view in building a relationship with disabled individuals. Sevgi (F, 45 years old) states that in Turkey being disabled is peculiar to low-income level, material deprivation and low socio-economic status. In line with Sennett’s (2003 cited in Sapey 2004) arguments, in this study it is observed that the strong emphasis on disabled people’s dependence and concerns about self-reliance negatively affect the issue of “respect” and eventually results in cultural subordination. Respondents complain to a great extent about misrecognition problems arising from institutionalized cultural patterns associated with disability.

> “People with disabilities are not respectful individuals in Turkey”. (Ahmet, M, 35 years old)
>
> “Dependent and destitute are the two attributes that best describe how society sees disabled people. My standard of living seems very surprising to others because I am disabled. But it is very normal for me. If you are disabled you should be destitute, that is what society expects and thinks about disability”. (Beril, F, 24 years old).
>
> “Society thinks that people with disabilities are needy, helpless, destitute, incapable, redundant and even problematical”. (Elif, F, 26 years old)
>
> “Being a disabled person in Turkey is living in a cell without a door because of social limitations”. (Aslı, F, 41 years old)
>
> “As a disabled individual you are incomplete”. (Ahmet, M, 35 years old)
>
> “We are 2nd and even 3rd class citizens. I cannot enjoy my rights as equally as others. Which school I can attend or what sort of jobs I can perform is determined by society and it is beyond my control. I cannot use public transport or socialize independently. I experience childish language and attitudes all the time. There is always agitation in the background. I feel like as if there is an invisible glass in front of me and I hit that glass each and every time”. (Ezgi, F, 33 years old)

> "One day a policeman told me that you are disabled and you smoke! plus you wear an earring! Because once you are disabled you are not allowed to do usual things that people do…"(Ahmet, M, 35 years old)

> "I believe that lack of social contact between society and people with disabilities and the lack of informative effort in our education system regarding experience of disabled people cause ignorance or misinformation. As a result administrators, teachers or students are treating or considering disabled individuals as people from other planets. They consider disabled person as a burden or additional duty. As long as you are not a threat as an additional duty, you are allowed to pursue your dreams otherwise no". (Sevgi, F, 45 years old)

> "One of my friends who uses wheelchair, has been looking for a job for 7 years and just because of her disability, she was not employed. This is the reflection of society's mentality about disability" (Beril, F, 24 years old)

> "When I was a student at university, people were trying to give me money even if I was not begging". (Aylin, F, 48 years old)

> "According to society, disabled people need help and charity because they are destitute and without charity they cannot manage by themselves". (Elif, F, 26 years old)

Through socially constructed cultural subordination, learned and shared meanings attached to disability, people with disabilities are presented as others or inferior peers who are not conforming to the "normal" world (Hannon, 2007). From societal perspective, there is a strong emphasis on vulnerability of disabled individuals and reinforcement of unequal relationship in which disabled people need the help of non-disabled ones.

4.2.1.1 The Effect of Low Societal Expectations on Reduced Capabilities

In line with Burcu's (2011) statement that disability has its real meaning in social and cultural context through interaction with other people, in this study, respondents frequently voice social restrictions imposed on disabled people as a reflection of social perception of disability. While society is criticized to define and perceive disability from medical model adopting hegemony of normalcy;

> "Society thinks that disability equals disease therefore I frequently hear get well soon wishes from people" (Defne, F, 19 years old)

> "The most important problem related with disability is "treating disability as a disease". Society considers disability as a disease. According to Turkish society, I am sick and unhappy. People think that I am an incurable patient". (Aslı, F, 41 years old)

> "People feel sorry for me and ask whether there is a cure for me. I laugh it off but I am sick according to them and they want me to recover". (Ezgi, F, 33 years old)

Disabled people mostly refer to social model of disability and underline the role of social, political, attitudinal, physical disabling barriers and prejudices on disabled people's experiences.

> "What makes us disabled is not "our impaired eyes, paralyzed bodies, impaired ears or our differently-abled brains or souls" but it is restricted, impaired thoughts and destroyed dreams that disable us". (Sevgi, F, 45 years old)
>
> "I am disabled because of disabling barriers set by others". (Beril, F, 24 years old)
>
> "I am not disabled. Even if you read the definition of disabled people, you will recognize that I am not disabled. Because according to the definition; disabled people are the ones who are unable to do their part regarding social life. Therefore I am not disabled". (Elif, F, 26 years old).
>
> "Disability is in thoughts and dreams. Other than that I don't know any disability". (Sevgi, F, 45 years old)

The experiences of disabled people reveal best how disability is culturally coded, perceived and treated by the society. The type and severity of the impairment, gender, economic conditions, available family support… etc. affect the uniqueness of experience but as respondents accentuate; form societal perspective almost every individual with disability is considered as having same experiences. However, despite the commonality of experiences mainly centering on low societal expectations questioning capability and restricting opportunities, male and female respondents bring different features to the fore regarding exclusionary processes. While women mostly attract attention on differentiated gender roles, childish attitudes and exclusionary approaches in education, male respondents mainly emphasize precluding role of disability, barriers related with participation into social life and dependency-creating circumstances, which may be related with, gender roles expecting men to be independent.

> "Dependence and barriers creating dependence are the most important problems". (Mehmet, M, 38 years old)
>
> "As a disabled person your life is very restricted with the rules set by non-disabled people. For instance, regardless of whether you have aviophobia or not, as a disabled individual you have to be seated in window side. What is funny is that they always find a way to justify their discriminative actions". (Ahmet, M, 35 years old)
>
> "When I go to watch football matches, I am sitting in a segregated area and I cannot be with my friends". (Mehmet, M, 38 years old)

> “Once the owner of a car repair shop added me on his phone book as disabled Ali. According to him, the only thing that defines me is my disability. Nothing more, he recalls me from my disability. It is annoying”. (Ali, M, 30 years old)

> “My disability got ahead of my invention. The press wrote about my disability more than my invention. Of course with a strong emphasis on “despite his disability”. The interview should have stressed my intervention but the focus shifted to my disability somehow”. (Mehmet, M, 38 years old)

> “Shall I help you? is the most frequently asked question to me. I hate that question. If I need help, I can ask for! They make you feel dependent all the time”. (Demir, M, 24 years old)

Whereas female respondents mainly refer to exclusionary approaches related with gender roles, emotional exclusion and education.

> “When you are a disabled person you are automatically exempted from social roles associated with gender. For instance I am a 33 year old, unmarried woman. If I were not a disabled individual, I am pretty sure that my relatives or my friends would have match-made. I would most probably hear phrases such as “there is a guy please meet him” But since I have impairment and I am a disabled woman, no one expects me to get married. In fact it even becomes a taboo so no one even mentions about it. According to society I am unfit to be a wife”. (Ezgi, F, 33 years old)

> “Even the accessible toilettes for disabled people are genderless. This is a reflection of perceiving disabled people as asexual creatures”. (Beril, F, 24 years old)

> “Disabled people frequently experience emotional exclusion. They encounter obstacles in their emotional relations due to the embedded disabled image. Disabled people cannot fall in love and pour their feelings out as easy as their peers do”. (Beril, F, 24 years old)

> “The most significant obstacle is being a woman in Turkey. If you are women, you are already disabled in a sense. The mentality that ignores which is different can ignore everything. That is why the fight against this mentality is necessary”. (Sevgi, F, 45 years old)

> “I could not enroll to the vocational school of health because I was not accepted due to my disability. It happened because one of the provincial directors of national education thought that disabled people are not competent enough to attend that school”. (Beril, F, 24 years old)

> “Education and employment have crucial impact on an individual’s development and almost always the choice about which school to attend, where to work and in which position depends on the circumstances influenced by societal perceptions and attitudes. Prejudices and attitudinal barriers prevent disabled people to follow their dreams and realize their potential”. (Sevgi, F, 45 years old)

> “When I first started my career as a teacher, I was supposed to have a certificate because I am a vocational teacher. However, they didn’t give me the certificate because of my disability. They did not believe that I could do it”. (Aylin, F, 48 years old)

> “My physical education teacher did not want me to attend PE courses. He ignored me. The day of our second meeting for PE course, my mother came to school and dictated to my teacher that her daughter would attend physical education classes no matter what. Therefore family and social relations play an important role when a disabled individual faces such discriminative attitudes. I experienced similar discriminative attitudes in a basketball match as well. I was a substitute player in our school’s basketball team. One day when one of the players got injured during game, as a substitute player I was supposed to play. But my trainer did not want me to play. He did not believe that I could play. He did not even want me to try. My teammates insisted that I should play. My experience clearly reveals how society perceives disability”. (Sevgi, F, 45 years old)

Respondents' experiences are in line with the "monopoly paradigm introduced by Silver (1995) because material and cultural privileges of non disabled people as well as the dominance of normalcy, restrict the access of disabled individuals to valuable resources such as education, accessible environments, employment etc. Within the scope of this study, respondents' experiences show that instead of one's abilities and goals, social forces and societal perception of disability determine to a great extent the occupation and work experience of disabled individuals or how they access to education and social life. This process is also fed culturally and the way disability is represented in the society.

This study reveals that society has very low expectations as far as disability is concerned. Due to accessibility problems often expressed by respondents, society does not encounter disabled people frequently during pace of life and when people meet disabled individuals, they feel sorry for them. Moreover, perceiving disabled people as dependent is so internalized that no matter how irrational requests and fund raising campaigns are, people would like to help without questioning the rationale and the outcomes.

> "Disability is associated with low expectancy in every sphere of live. There is even no expectancy at all. People are so surprised and they appreciate me because I am both disabled and have a valuable life". (Sevgi, F, 45 years old)
>
> "Society does not encounter disabled people on streets or in social life and when they meet disabled people, they feel sorry for them. I expect from society to stop pauperize disabled people and to stop make them dependent on charity. Instead I want to live in a society that creates necessary conditions allowing disabled people to live without charity". (Beril, F, 24 years old)
>
> "Nothing seems odd at all when the subject is disabled people. If any of the NGOs not specifically in the area of disability announces that they need to fund raise to arrange transportation for one of their activities, their campaign will be considered weird. But when the subject is disabled people, society unquestioningly supports and contributes to such activities. No matter how odd it is" (Ali, M, 30 years old)
>
> "Direct discrimination is inevitable for disabled people. Because people with disabilities are considered as a burden, they cannot attend the school they wish to attend or according to society the only suitable job for them is seen as telephone operator. In other words, disabled people are not even equal in terms of the possibility to realize their potential and pursue their dreams". (Ezgi, F, 33 years old)
>
> "Low expectations from society are also valid for the family members of people with disabilities. They believe that unlike any "healthy" individual, their disabled son or daughter is not able to perform any job. There are limited options for them. The day from my first day at work until my retirement this perception and prejudiced attitudes about people with disabilities did not change. Still they think that disabled people can only work at positions that do not require mobility or high qualifications". (Sevgi, F, 45 years old)

Low expectations about disabled people not only affect “reduced human capabilities” (Sen, 2000) but also result in disabled people’s chronic efforts to “prove” themselves and make society reconsider that disabled people are better than what people think. Among respondents there is general consensus that people with disabilities need to make more efforts than their peers to reestablish their identities. However unlike the strong emphasis on individualized efforts, there is a lack of reference to collective action that can challenge societal perception.

> “In order not to be excluded as a disable person, you have to perform 4 times better. You have to graduate from best schools, be able to speak several languages, make a difference at work in order to be seen as an individual like your peers” (Ezgi, F, 33 years old)
>
> “The societal expectations are very low for disabled people. They do not expect me to get out of the house. But I feel obliged to prove myself. I make effort every day to prove that I am more than the commonly accepted disabled image. However 70% of disabled people tend to fulfill societal expectations and stay in the house and do nothing. As a disabled person, you have to prove yourself, establish good relations and have good communication skills. In other words, you have to put much more efforts. At first you start with showing yourself as best as you can, then you try to show and prove that you are capable”. (Elif, F, 26 years old)
>
> “I am a METU business administration graduate and I had severe difficulty to find a job. During my first work experience, I was working in a position requiring high school qualification. In the course of time, people who you work together realize your qualifications. But to reach this stage you need to prove yourself. When you are a disabled person, your qualifications on your CV do not mean anything unless you prove them”. (Sevgi, F, 45 years old)
>
> “Disabled people make more effort to prove that they are better than what society expects from them. I am tired of fighting against the social perception of disability. Society considers us as unnecessary”. (Ezgi, F, 33 years old).
>
> “I am sick and tired of experiencing discrimination, inequalities, and injustices as well as questioning eyes that expect me to prove my abilities each and every time”. (Sevgi, F, 45 years old)

4.2.1.2 Hypocritical Appreciation of the Society

When disabled individuals perform beyond societal expectations and social roles envisaged for them such as pitiful, dependent, needy etc, they are praised and seen as heroes or heroines. Almost all the respondents stated that they are praised by society. But at the same time they attract attention to societal “hypocrisy”. Although society praises disabled people, at the same time they continue to hold prejudices against disabled individuals. People with disabilities complain that despite societal appreciation, people still continue to restrict opportunities and maintain their role in reducing human capabilities for disabled people. In a sense, society is paying lip service and widens the gap between the “hero” disabled who satisfies normality and the ones who are victimized. People instead of updating societal perceptions about disability personalize appreciation and success and often react by saying “you are not disabled” or “I do not consider you as a disabled person”. Consequently, society upgrades disabled individuals whom they are praising to non-disabled category and still continue to hold prejudices against disabled people as a homogenous category and restrict their access to employment, education and social life.

> "You are not like a disabled person” is a commonly heard sentence from others. Because I had proper education and worked for several years and I live a life not expected from a disabled person, people do not consider me as disabled. When I talk about disability rights, they criticize me and ask why I am talking. Because according to them, I am not disabled”. (Sevgi, F, 45 years old)
>
> “The expectations are so low that I am praised very frequently”. (Ahmet, M, 35 years old)
>
> “I am not respected and not considered as an independent individual. No one expects anything from me as a disabled person and if you ever succeed something you become a super hero”. (Ezgi, F, 33 years old)
>
> “I often hear phrases as I admire your optimism and energy. According to non disabled people, I have to be weary of life due to disability”. (Ezgi, F, 33 years old)
>
> “I hear lots of compliments and praises from people but at the same time I am in a very disadvantaged position as compared to the rest of society. There is this hypocrisy. On one hand they praise you, but on the other hand nothing changes in practice. They still hold their prejudices about disability”. (Beril, F, 24 years old).
>
> “On the one hand people say, “Bully for you! Well done!” but on the other hand they think that you cannot perform well when it comes to employment or education. I had such an experience as well. My supervisor, who praises me a lot, told me “If you were not disabled, you are the best available candidate for that position”. This is hypocrisy”. (Ali, M, 30 years old)
>
> “I don’t expect anything from a society which believes that “a blue lid can change the lives of disabled people. People are hypocrite”. (Demir, M, 24 years old)
>
> “I live in a hypocrite society where people collect blue lids for "me” and at the same time say that "look at the beautiful woman next to this CRIPPLE”. (Ahmet, M, 35 years old)

4.2.1.3 Attitudinal and Linguistic Subordination

In addition to attitudinal barriers, discourses, communication, media representation, symbols and language are inseparable part of cultural representation of disability. In this study, Begum’s (1992) statement; “stereotypes of passivity and childlike dependency are created for the members of the disabled and the roles prescribed render disabled people powerless” is confirmed through respondents’ experiences. Childlike conversations, use of childish language, caressing the head, asking questions to companion rather than directly addressing disabled individuals are among common experiences because of being seen as childlike, dependent, and powerless. The linguistic subordination is interconnected with attitudinal subordination and worsens the degree of socio-cultural exclusion.

Use of informal language regardless of the context and using medical terms that define medical conditions of disabled people such as autistic, hunchback, spastic etc. to humiliate and insult people are reflections of cultural subordination taking place between two unequal and mutually exclusive groups as disabled and non-disabled people. Moreover, initiating communication on the ground of charity campaigns and asking details about charity reveal the content and degree of superficiality of the distant interaction between disabled and non-disabled people.

> "People do not even address me in a formal way no matter how formal is the context. Because for them, I am not a respected member of the society". (Ahmet, M, 35 years old)
>
> "Because of disability, you are not seen as an independent individual. If someone would like to ask you something, he/she directly addresses the companion. They do not even expect that you can answer. Since you have impairment, they automatically think that you are not able to answer". (Beste, F, 42 years old)
>
> "I experience childish attitudes all the time. I am not respected attitudinally and verbally. Once I went to the restroom while at work and our cleaning lady greeted me like 'Oh my sweetie you're coming in here?' Well yes I am but I'm not your sweetie, I'm a grown woman you just met in a workplace."(Ezgi, F, 33 years old)
>
> "I am not seen as an independent individual; people ask questions about me to my mother rather than asking me". (Deniz, M, 44 years old)
>
> "Where shall I take these blue lids? is the most often asked question to me. As a disabled individual, I am expected to know everything about charity campaigns. When I am not able to answer, they look at me oddly". (Ezgi, 33 years old, Programmer, Paraplegia 95% extent of disability)
>
> "To hurt me, they called me hunchback". (Selim, 50 years old, Retired Civil Servant/ Active Trainer, Scoliosis 40% extent of disability)

The language and the way society communicates with disabled people give clear clues about how society interacts with disabled people and shape meanings as well as experiences. Respondents to a great extent stated that they are considered as a patient in need of cure or pitiful victims of disability. Therefore, they frequently receive get well soon wishes from people they have not met before with a sad sound in the background. In a sense, disability is treated as a temporary disease that should be cured. Although there have been legislative amendments incorporating strong social references into disability definition in the law, it is found out that change in the mindset of society is harder than legislative efforts and requires multidimensional focus. According to respondents, societal perception as well as responses to disability are still stuck the in medical model of disability in Turkey.

> "I hear get well soon very frequently from people I met for the first time. It is as common as saying a hello for them." (Elif, F, 26 years old)
>
> "When someone says "get well soon", I am really wondering why? It is very interesting because ultimately, I am not sick at all." (Beril, F, 24 years old)
>
> "Hearing "get well soon" so frequently reflects opinions of people. According to them, I have a disease". (Ezgi, F, 33 years old)
>
> "People are agitating all the time. When they see me, they say: Oh my dear, you are so beautiful[8]"(Defne, F, 19 years old)
>
> "I am not sick therefore I cannot understand why people keep saying, "get well soon" to me." (Ali, M, 30 years old)
>
> "To compliment and praise me, people say that they are not counting me as a disabled person. According to them, I look so healthy that as if I am going to walk. This is a compliment for them because from their point of view, being disabled is the worst thing that can happen to a person". (Ezgi, F, 33 years old)

4.2.1.4 Media Representations of Disability as a Source of Socio-Cultural Exclusion

Imagery and the way disabled people are represented shape cultural construction of disability through reinforcing stigmatization, prejudices and exclusionary patterns (Hutchison et al, 2007; Abrams & Christian, 2007; Hevey 1992; Taylor 2008; Çayır & Ergün, 2013; Pirsl & Popovska 2013). Since media representation and portrayal of disability in the textbooks of Turkish education system strongly adopt dominant view of normality and problematize physical difference not conforming to ableist standpoint (Çayır & Ergün, 2013; Akdağ et al. 2011) they are powerful sources in shaping disability experience. Within the scope of this study, respondents critically refer to problematical media representation portraying disabled people either as victims or exceptional heroes. Prioritizing tragedy or success stories of disabled individuals have close connections with socially embedded disability image avoiding ordinary experiences. When respondents elaborate on media representation of disability, they raise a common voice against marginalization stemming from

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[8] With a pitiful gesture

equalizing disability with personal tragedy. However there is not a similar consensus about the impact of success stories. From disabled people's point of view, the way success stories represent disability is also problematical somehow. The use of strong pitiful expressions such as "despite his/her disability" puts success on the back burner and eventually promotes haplessness of disabled individuals. In a sense media representation provides an ideological pretext for prejudiced disability perception and misrecognition problems.

> "Even when publishing a success story, media agitates and shifts attention from success to pity". (Beril, F, 24 years old).
>
> "There is always a trace of personal tragedy in the background. What a pity! and "poor girl" is repeated very often". (Beste, F, 42 years old)
>
> "No matter what is the content of news, disability related information dominates everything" (Demir, M, 24 years old).
>
> "Disabled people can only be heroes or victims. There is no other option according to media". (Sevgi, F, 45 years old)

4.2.1.5 The Role of Society in Subordination

In this study, due to embedded needy and useless image of disabled people, respondents critically refer to society's position with regard to charity and attract attention on society's role in subordination rather than questioning underlying causes of charity. Disabled individuals disapprove society's choice about easing their conscience through help in a visible, temporary and dependence creating way. The emphasis on "salving or easing one's conscience" confirms the assistance model set out in Ravaud and Stiker's (2001) analysis where "individuals receiving help are part of society by the virtue of society's concern for them". Accordingly, a form of social exclusion is created through "societal virtue" by establishing a subordination relationship where the beneficiary is perceived dependent on the benefactor. Moreover, society is motivated to undertake state's liabilities through emotional exploitation and activities of disability related NGOs.

> "The conscience of society plays an important role in charity activities". (Beril, F, 24 years old).
>
> "The commonly shared feeling that society should help disabled people; itself is a reflection of injustice. At first, personally it is offending and insulting. Secondly through the act of helping you restrict capabilities of disabled people by having done instead of letting them do. Moreover, you made disabled people feel dependent even if they don't feel that way before". (Elif, F, 26 years old).

> "When someone says "how did you manage all that "despite your disability", everything is ruined. It is better not to be praised when someone adds "despite your disability" at the end of the sentence". (Beril, F, 24 years old).
>
> "Turkish society is so unenlightened and uneducated that they are easily biased through emotional exploitation". (Aslı, F, 41 years old)
>
> "Society considers disabled people as a mean to salve their conscience". (Selim, M, 50 years old)
>
> "I think that non-disabled people use disabled people to get big hand for and to be applauded". (Beste, F, 42 years old)
>
> "Society greatly supports charity related with disabled people because of salving their conscience". (Aslı, F, 41 years old)
>
> "I can draw an analogy between disabled people and street dogs. Just as street dogs are seen as problems because of their never ending existence and need for care and food that stimulate guilty conscience as well as regret, disabled people also arouse similar feelings in society. The problem is there and people cannot find any permanent solution. Instead they ease their conscience by helping disabled people just like they are feeding street animals. But if you feel responsible, you need to take responsibility!" (Sevgi, F, 45 years old)

As this study reveals; the idea "let's address material deprivation first then we can deal with disabled people's image" worsens the oppression because economic and cultural injustices are not mutually exclusive. Instead they are intertwined and equally important in shaping disabled individuals' experiences. Accordingly, cultural meaning attached to disability that involves cultural codes and expected roles about disabled individuals is influential in defining interaction between disability, charity and exclusionary processes. Lastly, in addition to the impact of cultural representation and social perception of disability, agency and disabled people's position with regard to charity are found as equally important features in this study.

4.2.2 Agency of Disabled People Leading to Social Exclusion

The dynamic relationship among disability, charity and social exclusionary experiences as well as the role of charity in this complex relationship is closely related with agency concept. Within the scope of this study, agency signifies active role of disabled individuals as cultural agents in shaping or re-shaping meanings and affecting social structure through their decisions and actions. Disabled individuals' influence in cultural construction is one the most important determinants in creating realities and how they experience disability.

Producing and maintaining group based social and economic hierarchy between low and high status groups are closely related with relationship and cooperation between these low and high status groups and how they reinforce group based inequality (Göregenli, 2012, p.69). Disabled individuals as being cultural agents play a crucial role in constructing group based hierarchy and inequality. From respondent's point of view, disabled people directly or indirectly affect various forms of injustices through their actions or inactions.

In this study, disabled people belonging to younger age sample give relatively greater reference to the role of disabled people as a crucial source in worsening socio-cultural exclusion and shaping the role of charity in disability. The way disabled people communicate with society directly affect cultural construction of disability and affect group-based inequalities.

> "The way disabled individuals explain their problems and present themselves are important factors in creating injustices. We are living in the age of communication. Now it is easier for disabled people to mobilize in order to change already stereotyped perception about disability. However they do not make any attempt and easily accept already determined image". (Ali, M, 30 years old)
>
> "Disrespectful attitudes of NGOs and state towards disabled people are related with activities of NGOs and how disabled people present themselves. People with disabilities' relationship with local governments and state trigger the disrespectful behaviors and attitudes towards them". (Ahmet, M, 35 years old)
>
> "According to me, the most important problem is communication; the way disabled people express themselves as well as how society understands them and reacts accordingly". (Elif, F, 26 years old)
>
> "Not being able to properly express themselves is the most significant problem of disabled people". (Selim, M, 50 years old)
>
> "Disabled people themselves are trigger factors behind disrespectful attitudes of NGOs and state". (Ahmet, M, 35 years old)
>
> "The biggest problem is communication. It affects social perception of disability". (Demir, M, 24 years old)

As interacting cultural agents within structural context, disabled people play a crucial role in promoting or challenging victimization as well as shaping the role of charity in disability. According to respondents, subordinate, devalued roles envisaged for disabled people are internalized, accepted and played by majority of disabled people. The agitation and helpless image contribute to victimization leading to increased support to charity that involves quick, superficial remedies for privatized disadvantages. Self-perception as well as how disability is promoted from disabled people's perspective is influential in this process. This study reveals that respondents are very critical about disabled people who make use of their impairment and allow NGOs to exploit disability. Disabled people, who accept to play the role of victim, are criticized because of playing into NGOs and state's hands. People who associate themselves with commonly accepted destitute, impotent disabled image and who reinforce subordination through victimization are seen as critical players in the popularity and continuity of charity campaigns and prejudiced attitudes of society.

> "The real problem is disabled people who victimize themselves. I know personally many people with disabilities who agitate themselves. Self-perception of disabled people is as important as how disabled people are perceived in society. According to me, the way disabled individuals present themselves is among the most important factors behind the popularity of charity". (Demir, M, 24 years old)
>
> "Not only society commonly equalizes disability with incapacity but also disabled people consider themselves victims of disability". (Ezgi, F, 33 years old)
>
> "Disabled people are very unfair to themselves". (Beril, F, 24 years old)
>
> "Society perceives disabled people the way they represent themselves. There are success stories but mostly disabled people represent themselves as needy and destitute. To a great extent, people with disabilities do not consider disability as a cause and a political issue". (Utku, M, 41 years old)

When respondents are further asked to elaborate on disabled people in Turkey, young male respondents voice strong criticism against the role of disabled individuals in maintaining pitiful attitudes towards disability. Moreover, the way respondents speak about disabled people in general reveals a clear differentiation they made as if there are two distinct categories. On the one side they refer to victimized disabled people and on the other side they differentiate those who refuse the role of disabled victim. Respondents distinguish themselves from victimized disabled people. According to young male respondents, on the one hand there are people who internalize subordination and take powerful structural players' side to benefit from their charity, on the other hand there are people who criticize being considered as victims and confront inequalities. In a way respondents disapprove incompetent role played by disabled people and distance themselves from disability identity.

> "There are two types of disabled people. The ones who internalize already embedded social perception of disability and the ones who tackle for their dignity and rights. There are some disabled people who say that "I am disabled and I need help" and there are others who make efforts for their life. These two distinct groups are far from each other. This is the problem". (Ali, M, 30 years old)

> "Disabled people like being on powerful side. Whoever is more powerful, they get along well. For that reason I do not expect any opposition to charity and political mobilization against current status of NGOs, because NGOs organizing charity campaigns are the powerful ones". (Demir, M, 24 years old)

> "The most dangerous issue is to use fictionalized stories and market sorrows that agitate and portray disabled people as helpless. People with disabilities do not maintain a stance against charity campaigns. Instead they wish for charity campaigns to continue". (Ahmet, M, 35 years old)

Similar to societal response upgrading disabled people to non-disabled category upon performances beyond expectations, respondents in this study also act in a similar way and prefer disassociating themselves with disability. They reject victimized role enhanced by majority of disabled people and choose to perform beyond expectations to challenge negative connotations associated with disability. During interviews, respondents frequently referred to importance of individualized efforts in changing social perception of disability. In a sense, they feel obliged to prove that disabled people are more than ascribed role of helpless victim. Rejecting disability identity together with a strong emphasis on individualized efforts rather than collective efforts appear as two important obstacles preventing disabled individuals' involvement in disability movement.

Instead of changing perception and fighting against multidimensional forms and sources of oppression through collective activism, younger respondents distance themselves from group-based identity and collective strategies. Although younger respondents attract attention to the importance of agency in stimulating social change, they mainly make reference to individualized efforts rather than collective ones. Rather than transforming the deficient features of disability movement, disabled people prefer to stay distant from disability activism and remain silent in terms of collective response. This tendency may be related with perceiving disability oppression as part of private domain, which reinforces internalization of individualistic efforts to prove their abilities. In a way, respondents prefer and value more the individualized forms of actions regarding disability advocacy. They do not believe that they have significant influence on policies as well as outcomes. They do not admit that their involvement can change anything in disability movement. Ultimately, disabled individuals are distant from collective advocacy because of involving more complex, onerous and long lasting processes regarding outcomes.

Disabled individuals' reluctance about engaging in collective strategies also sheds light on in-group dynamics of disability. As Sevgi (F, 45 years old) shares her experience, there is an endless competition to rank disadvantages, to prove who is more disabled and who deserves more. It can be argued that due to internalizing absence of universal coverage and limited resources of state and NGOs, each impairment category makes efforts to prioritize their problems first and underestimate the rest. Even in the same category of impairment such as orthopedic disability, group members rank experiences and disadvantages. Each individual prioritizes and makes society prioritize his/her disadvantages more. In the end rather than adopting common stance against disability oppression, a competition of ranking disadvantages based on severity of impairment takes place.

> "Each impairment category thinks that their problems are more important and severe than others. As if there is a competition questioning whether you are more disabled or I am. There is even discrimination among different impairment categories because everyone thinks that their problems are more severe and important". (Sevgi, F, 45 years old)

How disabled people perceive their experiences have influence on their strategies and actions. When people with disabilities privatize disadvantages they are experiencing, the coping strategy points individualistic forms of actions. During interviews, as expressed by respondents, disabled people face various forms of exclusion. However injustices are so internalized by disabled people that despite of referring various exclusionary examples, still they are reluctant to say that they are excluded. Therefore the way people with disabilities perceive their experience is influential in engaging in activism or not. The internalization of subordination and learned helplessness prevent them being part of political mobilization and involvement in NGOs as well.

Herein, it is important to recall Koray (2005) who asserts that it is economically powerless and disadvantaged classes' quantitative power and to what extent their power leads to socialization and politicization that make change state's understanding in terms of performing its social responsibilities. Therefore, collective strategies and activism are crucial in transforming existing inequalities. However in order to gather around common cause, firstly disabled people should be aware of their rights.

During interviews, all respondents regardless of age and gender were very hesitant while talking about their rights, national and international laws or policies directly influencing their lives. When they elaborated on their knowledge related with legislative framework about disability, they waited for approval about the answers they gave with a hesitant face. Their knowledge mainly originates from needs based drive and centers on exemptions and affirmative remedies provided by state. It can be say that they are not well aware of their rights arising from national and international law and not very interested in defending or expanding them.

The lack of knowledge about disability rights can be a source of the missing enthusiasm in collective disability advocacy. This situation also gives clues about future projection of disability movement in Turkey and why respondents are reluctant and pessimistic about disability organizations and collective actions. Lack of organized and conscious people aware of their rights plays a crucial role in how NGOs set its priorities as well as the effectiveness and appearance of charity. Accordingly, interviewees do not expect any activism that can trigger political mobilization against charity or disability oppression in near future.

> "The current understanding of NGOs and their activities are unable to give disabled people hope. Instead they are stealing energy and hope. Being on the same opinion with NGOS is like an insult for me. How can I engage in NGO activities when I am not speaking the same language with NGOs?" (Ezgi, F, 33 years old)
>
> "I am old enough now, but I am worried for disabled youngsters because I am hopeless for the future". (Beste, F, 42 years old)
>
> "People with disabilities should be active in defending their rights. Personal as well as organized efforts are very valuable but disabled people are silent". (Sevgi, F, 45 years old)
>
> "Unless disabled individuals take the leading role in challenging problems, no one will do it for us". (Ahmet, M, 35 years old)
>
> "There is no common stance regarding charity among disabled people". (Aslı, F, 41 years old)
>
> "There is not a shared concerted action against charity campaigns. Everyone including disabled people and those donate seems happy and self-complacent about charity". (Sevgi, F, 45 years old)

In this study, it is revealed that agency and actions or inactions of disabled people are very important determinants the way society as well as state treats them through its policies. Together with NGO activities, self-perception and how disabled people define their experience are crucial factors affecting disability oppression, the role of charity in disability and the degree of exclusion.

4.2.3 Social Exclusion of Disabled People through Religious Motives

In this study, almost all of the respondents refer to the influence of religion in determining significance of charitable dominance in disability. As previously discussed in conceptual framework, long before being considered as medical or socio-political construct, disability was associated with punishment from God due to immorality or sin and disabled people have been subject to various forms of punishment and exclusion (Clapton & Fitzgerald 1997, Arıkan 2002, Grech, 2009, Braddock &Parish, 2001). In addition to demonological connotations associated with disability, disabled people are represented as charitable objects to fulfill religious duties and a way to ease conscience. Therefore throughout the historical process, religion has had a great impact on how disabled people experience disability.

Despite various disability models' chronological assessment predominantly associating pre-capitalist era with the religious model, capitalist era with medical model of disability and recent period after 80's with a fragmented analysis of disability, it is not possible to limit the impact of religion on disability with a specific era. As being one of the most influential features of a culture, religious motives even today are important sources for marginalization of people with disabilities and reinforce to a great extent the individualization of disability. The tendency to associate disability with misfortune, sin, immorality and punishment is still valid for today and it reveals itself via idioms or social expressions in daily life.

In Turkey, it is still very common to hear; if you argue with your mother or parents, your hand or body will be impaired because of God's punishment. Therefore religion appears as an important source in determining societal perceptions, attitudes as well as fear associated with disability. Again the degree of charitable dominance in disability is closely related with Islamic ethos that promotes moral and religious duties of decent people to help those in need. Herein, it is important to recall the report about "Disability in Turkish Textbooks" (Çayır&Ergün, 2013) which reveals that in the textbooks of religious culture and moral knowledge course, disabled people are frequently portrayed as sick, destitute, helpless, poor, powerless individuals and charity based approach to disability is offered as an effective way for reintegrating disabled people into society. Helping needy disabled people is presented as doing a good deed and a key to a better life after death for benefactors. Therefore not only pitiful feelings but also worshiping through helping disabled people mobilizes society to support disability related charity activities. Respondents' opinions and experiences also reveal the influence of religion in individualization of disability oppression and increasing support for charity targeting disabled people.

> "For non-disabled people, donating to disability related charity campaigns is the easiest way of worshipping; you give 1 or 5 liras and guarantee heaven. Religion and doing a good deed have great impact on supporting charity and treating disabled people helpless". (Utku, M, 41 years old)
>
> "Religious effect is very influential in mobilizing people to donate for disabled people. Non disabled people's charity perception is different from disabled people's charity perception due to its emotional dimension". (Demir, M, 24 years old)
>
> "Culture and religion is very influential in charity campaigns. Islam aggrandizes helping each other". (Aylin, F, 48 years old)
>
> "In Turkey, the easiest and most successful exploitation is performed concerning disability and religion". (Ali, M, 30 years old)
>
> "Turkish society has a conscience. This is very influential in charity. And of course religion! According to me, the most important factor behind charity is religion!" (Elif, F, 26 years old)

In addition to the influence of Islam in shaping the role of charity regarding disability, considering disability as an outcome of sin and punishment from God is so internalized by society that non disabled people often feel sorry for their disabled peers and do not hesitate to express their sadness for unfortunate ones. Soon after asking the medical condition of disabled individuals they have met for the first time, people try to praise other personal characteristics such as beauty or intelligence and refer to a better life after death that is well deserved by disabled people because of already enough suffering in this life. Within the sample of this study, non-disabled people's interaction with disabled people reveals lots of religious references and pitiful feelings. The experiences of respondents clearly reflect societal attitudes adopting the religious model of disability.

> "In our society where fate, fatality and predestination are valued to a great extent, it is very common to equal disability to misfortune and ill-fated disease". (Elif, F, 26 years old)
>
> "Disability is associated with sin and shame of impaired individual or his/her family. Hence it is believed that disability is related with the will of God". (Demir, M, 24 years old)

> "May God heal you!! People are always wishing that Allah should help me. But why? Why should Allah needs to heal me if she does not heal your impaired brains?" (Demir, M, 24 years old)
>
> "Since we, disabled people, are helpless, we need God to help us". (Demir, M, 24 years old)
>
> "Oh my dear, do not be sad. Allah impaired you in this world, but in heaven you will have a wonderful life". (Ahmet, M, 35 years old)
>
> "This boy is very clever! Allah has impaired you, but at the same time Allah gave you more intelligence". (Ahmet, M, 35 years old)

Respondents' experiences reveal that societal perception of disability is still stuck in between the medical and the religious model of disability where disability oppression is considered as an outcome of combination of sin, immorality, punishment, biological inferiority and impairment rather than a political issue. In this study, religion is identified as one of the most significant sources behind a charity based protectionist approaches to disability that promotes individualization of disability oppression influencing the dynamic relationship between disability, charity and the degree of social exclusion.

4.3 Charity as a Source of Socio-Cultural Exclusion

From the results of many previous studies and from the study of this thesis, charity activities in the context of disability are determined as powerful sources behind socio-cultural exclusionary processes experienced by disabled people. This section deeply analyzes the complex interplay between charity activities and exclusionary patterns.

4.3.1 Charity as an Illusion

First of all, in this study when disabled respondents are asked to share their views about charity campaigns related with disability, almost each of them overwhelmingly referred to "blue lid campaign"[9] (mavi kapak kampanyası). Although charity

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[9] In Turkey, one of the most widely known and accepted charity activities for disabled people is the blue lid campaign (mavi kapak kampanyası) introduced in 2010. Soon after the campaign has been launched, it became widespread all over the country with an aim to supply wheelchairs in exchange of plastic bottle lids to those who need a wheelchair. It is a voluntary project that gains great acceptance, popularity and participation from society.

campaigns related with disability cover a broad range of activities, due to its visibility and popularity, blue lid campaign happens to be the most known and criticized one.

From respondents' point of view, although charity activities bear positive motivation, they worsen disability stereotypes and demean disabled people by representing them as destitute, powerless, needy, pitiful and dependent individuals. Disabled people frequently refer to the side effects of blue lid campaign and underline its detrimental effect especially on next generations' perception of disability. Since disabled people hardly ever exist in mainstream culture other than being presented as needy, pitiful and destitute, the way charity portrays people with disabilities are very influential regarding the social perception of disability. Moreover according to respondents, representing charity -especially wheelchair provision- as a major solution to disablement results in an illusion that problems are solved.

> "The act of helping and the intention behind it is very good, however the outcomes are not". (Demir, M, 24 years old)
>
> "One day an old man asked me whether I have had my wheelchair through blue lid campaign. Society thinks that by collecting blue lids, they help disabled people to have active and useful wheelchairs. However reality is not like that. Besides that old man felt sorry for me! This is the real consequence of these campaigns". (Aslı, F, 41 years old)
>
> "Society at large becomes aware of disability through charity campaigns such as collection of blue lid for provision of wheelchair. That is why provision of wheelchair is the first thing that comes to the mind of society when the matter is disabled people. Eventually it is normal for society to think that wheelchair is the sole problem of disabled people because this message is given all the time" (Beril, F, 24 years old)
>
> "Blue lid campaign is the most known and supported charity campaign by society because it is easy and everyone can do it. It does not require 1000TL worth of donations. Society feels like they are doing something for disabled people". (Elif, F, 26 years old).
>
> "The real and significant problem is that even children contributed to the blue lid campaign and collected blue lids. Children's perception about disabled people is shaped by such a wrong campaign, can you imagine? These charity campaigns not only affect today but also destroy tomorrow. The next 30 years are affected with the blue lid campaign". (Ahmet, M, 35 years old)

4.3.2 The Role of Charity in Promoting Unequal Relationships

The findings of this study suggest that charity campaigns' strong reference on normality and medical aspects of disability strengthen the categorization between disabled and non-disabled people. In a way, charity undertakes a role of care and cure and while doing so becomes a source of oppression for disabled people as a category. 1st stage of Hevey’s charity analysis explains clearly the situation in Turkey where NGOs underline the importance of charity by presenting hopeless disabled images -usually children- photos and offer charity as a vital solution. Below seen images are some of the examples from interviewed NGOs’ charity advertisements. Through these advertisements ‟selling fear and promoting a brand not to buy, but to buy your distance from” (Hevey, 1992) is satisfied.

In the first two advertisements, 1st stage of Hevey’s analysis in which a negative, agitated child photo together with a positive text portraying hopeful future through charity is promised. Overall, charity activities are presented as useful means for overcoming obstacles and ensuring independence for disabled people without any reference to political action. In a sense, providing assistive equipment is presented as a panacea for all disadvantages and injustices faced by disabled people.

“Let’s be their hope! Do you know that thousands of destitute disabled brothers and sisters are waiting for wheelchairs?”

Figure 5. Charity advertisements of NGOs Sample 1

“Be hope for those who dream independence”

Figure 6. Charity advertisements of NGOs Sample 2

“Let’s collect blue lids and overcome obstacles”

Figure 7. Charity advertisements of NGOs Sample 3

“It is just a blue lid for you, but for them? Independence”

Figure 8. Charity advertisements of NGOs Sample 4

“Today you are healthy, but what about tomorrow?”

Figure 9. Charity advertisements of NGOs Sample 5

“We run for those who can’t.”

Figure 10. Charity advertisements of NGOs Sample 6

Within the scope of this study, Hevey’s (1992) analysis about charity advertising mirrors well the dominance of medical model of disability and the stimulation of fear and pity to make non-disabled people donate in Turkey. Both the visuals and language promote charity as a vital solution to address disabled people’s exclusion. Hence, disability is depoliticized and used in a way to distance non-disabled people from their vulnerability.

4.3.3 Charity as a Source of Non Disabled People’s Subjectivity

The language, visuals and discourse employed by NGOs’ representative during interviews, in their web sites as well as the focus of activities centering on charity reveal that disability NGOs in Turkey promote pity, fear, tragedy to motivate society to donate and internalize “help us to help them” understanding. Rather than making non-disabled people question their role in disablement, an easy option of “donate and get rid of your responsibilities” is offered. NGOs continue their existence through promissory discourse that adopts non-disabled people’s standpoint aiming to fix “impaired body”. Accordingly charity campaigns offer non-disabled people an opportunity to contribute to normalizing disabled people as best as they can. While charity activities are presented as beneficial intermediaries taking from the advantaged ones and giving to the disadvantaged people, people with disabilities are further portrayed as needy, vulnerable, impotent and in need of normalization. In the end, what is initially seen as being repaired with the right hand is ruined with the left hand.

> “Charity campaigns for disabled people seem to take from the rich and give to the poor; however in reality they damage equality among citizens. Although charity campaigns seem to ease the burden on the state, charity activities promote disabled people as destitute and helpless consumers. Such perception also leads to question the productivity and ability of disabled people in other areas. In the end whether NGOs ease the burden on state or not is very questionable”. (Ezgi, F, 33 years old).
>
> “The implicit message is that “give a blue lid and get rid of your responsibilities” (Aslı, F, 41 years old)
>
> “I am not interested in disability related NGOs at all. They are unnecessary and do nothing but harm. They gather disabled people together and pile on the agony”. (Elif, F, 26 years old)
>
> “Charity activities contribute to worsening images of disabled people by portraying them as poor and destitute. If charity campaigns adopt a holistic approach then they may be useful. Otherwise helping an individual does not mean anything if he/she is still stuck at home. For me, this is not helping at all”. (Beril, F, 24 years old).
>
> “Charity campaigns create vicious cycle. Collecting donations for people with disabilities reinforce the idea that disabled people are needy and vice versa. A chicken and egg situation is created”. (Elif, F, 26 years old).
>
> “I don’t think that charity campaigns managed by NGOs are effective and beneficial. They present people with disabilities as dependent, helpless and needy”. (Aslı, F, 41 years old)

Ahmet (M, 35 years old) criticizes commonly supported charity campaigns because they promote an unequal relationship between non-disabled and disabled people. He underlines the detrimental effects of charity on social perception of disability by giving reference to the unsuccessful political mobilization attempt they initiated so called “we are not brothers or sisters of anyone”.

> “To trigger political mobilization among disabled people, we initiated a campaign called “we are not brothers or sisters of anyone”. We are not equal with non-disabled people regarding participation in educational, social or work life… But all the time there is agitation

> and everyone voices "our disabled brothers". Brotherhood has its roots in familial relationship and when one of the siblings wears good clothes, technically so does the other sibling. More or less they share the same opportunities. But there is not such a brotherhood between disabled and non-disabled people. There is not an equal relationship. I do not want to be a brother of anyone. I cannot even walk independently with my wife on streets. How can they talk about a brotherhood?" (Ahmet, M, 35 years old)

4.3.4 Charity as a Source of Discriminative Practices

Although during interviews, NGO representatives gave some reference to awareness raising campaigns and rights based approaches, disabled respondents criticize NGOs due to the contradiction between their actions and discourses. Messages as "taking necessary measure to prevent disability" and "relieving the consequences of disability" are frequently used by NGOs in their web sites. Heavy dominance of medical aspects undermines the effect of rights based discourses. For instance, NGO 6 claims to be a rights-based organization for disabled people, however within their awareness raising activities, presenting disability as a threat is commonly used by strongly voicing "disability could also happen to you". There is very limited emphasis on equal rights arising from equal citizenship. Instead messages with a fearful tone transmitting "understand disability because it could also happen to you" are widely used.

Frequently used mottos as "today you are healthy, but what about tomorrow?", "disability could also happen to you", "all nondisabled people are potentially disabled and most nondisabled people may become disabled to some extent with age", "it is just a blue lid for you, but for them? ", "you can be the hope of children waiting for wheelchairs", "collect blue lids one by one and overcome obstacles step by step", "run for those who can't run", "do you know that thousands of destitute disabled siblings are waiting for wheelchairs from our NGO", "your support can vivify them", "let's be their hope" etc. are equalizing disability with impairment and promotes tragedy, fear and pity. Respondents are very critical about the influence of disability NGOs' discourses in worsening exclusionary processes.

> "Everyone can experience disability one-day" means that bad lottery can find you as well. The message is very bad". (Sevgi, F, 45 years old)

> "Discourses employed by disability related NGOs are very problematic because given message makes disabled people's enjoyment of rights conditional on non disabled people's probability of being disabled. Briefly there is a conditional equality. It also stimulates fear. And it feels like if there is a guarantee that non-disabled people will never ever have

> impairment, they will disregard disabled people. It feels like people defend accessible environments or ramps for me because of their possibility to experience disability one day" (Ezgi, F, 33 years old).
>
> "NGOs trade emotional exploitation. I like the spirit of civil initiation but not disability related NGOs' spirit. Their messages and activities do not match and vary to a great extent". (Demir, M, 24 years old)
>
> "If NGOs present/market disabled people like you or me, they will not be able to raise funds. They need agitation. Because there is expectation of tragedy about disabled people in the society as well". (Elif, F, 26 years old)
>
> "These discourses are widely used by NGOs however I cannot see their reflection in my daily life. Although messages of NGOs claim to enhance empathy, in the end nothing changes. People still continue to park in disabled people's car parking area. So messages given by NGOs and their discourses are just meaningless sentences". (Aylin, F, 48 years old)
>
> "Yes everyone can experience disability, there is a probability. But to do something, to change things, not everyone should be disabled. It is very irritating to think that way…" (Beril, F, 24 years old)
>
> "The discourses voiced by NGOs are very weird and cliché. The message that disabled people are freaks and you could be like them is implicitly given all the time. Fear is promoted". (Aslı, F, 41 years old)

In accordance with Shakespeare's (2006) analysis of "charity as a provider", charity activities differentiating one particular type of impairment from the others are also identified as a source of exclusion in Turkey. As part of this study, the ubiquitous use of wheelchairs in charity campaigns and associating the wheelchair as an indispensable symbol of disability not only result in society to overemphasize material deprivation of a particular disability group over other sources of oppression but also reinforce certain kind of impairments to dominate disability experience. This situation also leads to differentiate disabled individuals who are not using wheelchairs as "non-disabled" and ignorance of diverse subordination and impairment experience. Apart from this study, I heard similar complaints several times especially from veterans injured during terrorist attacks in southeastern region of Turkey. The ones with lower limb amputation complained that since their impairments are not as visible as a wheelchair, they are not seen as disabled as a wheelchair user. Though they also belong to orthopedic disability group, society tends to rank disabled individuals based on the visibility and severity of impairments. In a sense a hierarchy of impairments is created. In this study, respondents also underline similar concerns in terms of ranking impairments.

> “Since I am not using a wheelchair and I can walk though just barely, I am not disabled for them. Despite the fact that our problems are similar, society and my friends do not count me as disabled”. (Sevgi, F, 45 years old)
>
> “Each impairment category thinks that their problems are more important and severe than others. As if there is a competition that questions whether you are or I am more disabled. There is even discrimination among different impairment categories because everyone thinks that their problems are more severe and important. There is no unity at all”. (Sevgi, F, 45 years old)

Another critical feature with regard to the activities of NGOs is the exclusionary patterns arising from eligibility criteria[10] of charity activities set by NGOs. This study also confirms Morris’s (1991) statement underlining the role of charities' deserving definitions in worsening injustices. Similar to state’s concern aiming to diminish burden by restricting who deserves more, NGOs also rank “needs” and differentiate “who deserves more” according to certain criteria such as income level, age, level of activeness, productive abilities and employability. In their words, NGOs have to make complex decisions about whom to select/target and who to leave behind. From NGO’s perspective, all these decisions involve complicated processes and choices due to restricted resources unable to respond all disabled individuals and their needs.

During interviews, NGOs frequently underlined the importance of objective and sound decisions in ranking and addressing “individual’s needs”. Decision making through executive board following an “informal” social assessment system as well as decision making through science and advisory boards are found out as the most common processes and procedures employed by NGOs. Accordingly, applicants are expected to satisfy an informal social assessment which examines medical reports evaluating physical, mental condition and extent of disability, economic conditions and disabled individual’s potential for participation in education and employment.

During informal assessment of individuals, requesting certificate of poverty issued by public authorities is a common procedure to identify the financial situation, which is a significant feature in decision-making. However the validity of certificate of poverty is also a concern for some NGOs (NGO 2 & 4). The suspicion can be interpreted as a reflection of trust issues between NGOs, individuals and the state.

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[10] Annex B

Consequently, trust issues and validity concerns about official documents in revealing actual situations; provide a basis for customized and subjective informal assessment systems for each NGO. When NGO representatives are asked to elaborate on informal assessment system, they barely give details by stating, “each case is a special case”. The customized informal assessment system employed by NGOs appears as a closed book that can be one of the reasons behind the trust issue between people with disabilities and NGOs.

> “We can identify who really needs help. Actually if a person does not need help, he/she will not come to us” (NGO5).
>
> “Everyone can have certificate of poverty, it is easy. Therefore, we can investigate better the actual situation of disabled people. We are the ones who fell from roofs so we can understand who fell from roof” (NGO4).
>
> “Priority is given to the most urgent applicants” (NGO4).

As part of informal assessment, without exception each NGO attracts attention to the significance of age and participation in education as the most crucial determinants for priority and charity eligibility. Accordingly, younger disabled people who are expected to have higher potential for level of activeness and students have priority when they apply to NGOs in order to address their needs. As disabled people get older, neither they become target audience for NGOs nor the state responds to their disadvantaged position with specific policies. It seems more usual or acceptable to associate disability with old age, which has an influence on prioritizing young ones and letting older disabled people deal with their problems alone. Eventually people experiencing disability at old age become more vulnerable to material deprivation with fewer opportunities to socialize and participate. Therefore similar to insufficient state disability policy, NGO activities and charity also result in exclusionary patterns where a great portion of disabled people is forgotten and further excluded through a set of priorities determined by NGOs.

The experiences of respondents reveal clearly the above-explained exclusionary patterns. Almost each respondent from older age sample stated that they or their peers have never been considered eligible for NGO activities such as summer camps, assistive equipment aids etc. and they expressed serious doubts about the objectivity of charity eligibility and the activities managed by NGOs. In this study, each of the respondents who received NGO charity or scholarship belongs to younger age sample or who happened to be students at the time when they were chosen for NGO charity.

> "Both the expenses of my rehabilitation in US and the cost of my wheelchair are covered by a NGO. Informal relations were influential when I was selected, besides I was a very successful student. My family's financial situation was insufficient" (Deniz, M, 44 years old)
>
> "Being selected was pure luck for me. I was lucky enough to be selected for assistive device aids and educational grant from TESYEV". (Elif, F, 26 years old)
>
> "I think in my case, being a successful student and lack of income because of still studying were influential to get a scholarship". (Demir, M, 24 years old)

Eligibility for assistive equipment aids, health operations or scholarship makes recipients feel "lucky". This feeling alone reflects well how a relationship of gratitude is created and oppression is internalized as a private issue. The strong emphasis on "feeling lucky" demonstrates the importance of personal relations, social networking and how selection process and charity system is fragile, uncertain, non-standardized and subjective.

4.3.5 Charity as a Reflection of Patronage Relationships and NGOs' Self Survival

In this study, disabled individuals who benefited or who are still benefiting from NGO activities and charity are more reluctant to criticize NGOs which can be explained as a micro level reflection of patronage relation between the state, NGOs and individuals. But when they are further asked to elaborate on charity activities, they also question and criticize the content and priorities of charity campaigns and disability NGOs.

> "I do not know any disabled people personally who have received aid from any of the charity campaigns managed by NGOs. Besides I have lots of disabled friends who need and applied to these campaigns. If these campaigns were righteous, I should have had at least one friend who received aid. I believe that these campaigns have secret agendas". (Beste, F, 42 years old)
>
> "Once, I met a person who collects money for disabled people on behalf of a disability related NGO and I said that I am also a disabled individual so you can help me. He apologized and run away. So I have enough experience not to trust in charities". (Aylin, F, 48 years old)
>
> "In order to test the reliability of charity campaigns that are managed by NGOs, one of my friends once called one of the NGOs in charge and asked whether they could help him for his prosthesis. They responded that at that time they were helping people with hearing impairment. Then my friend called again and presented him as a hearing impaired person and asked for help again. That time NGO representative said that they were helping visually

> impaired people. In fact NGOs organize charity campaigns for raising funds for their organizational expenses. It is not surprising because these are big organizations with lots of secretariat and consultancy expenses" (Utku, M, 41 years old).

In addition to transparency concerns expressed by respondents, trade emphasis in charity activities plays a crucial role in distancing disabled people from engaging in NGOs, which ultimately make them become "organizations for" disabled. The lack of efficient monitoring by the state institutions worsens the situation as well.

> "There is a huge unearned income in charity activities. Besides there is a mutual interest relationship between assistive device suppliers and NGOs. Companies who generate income by sales of assistive device through charity system also provide benefits for those who choose them as supplier" (Sevgi, F, 45 years old)
>
> "Charity campaigns are totally trade". (Beste, F, 42 years old)
>
> "I believe that there is too much unearned income in charity business because the amount of collected money exceeds what is given to disabled people". (Aylin, F, 48 years old)
>
> "Once I had an experience about wheelchair provision. As national team we were preparing for paralympic games and the national paralympic committee[11] informed us that they would provide us wheelchairs. Despite the fact that I specified what I needed, they provided us what they wanted. NGOs pretend to satisfy needs of disabled people; their real intention is not understanding and finding personalized solutions to the needs of disabled people. In the end, yes they provided us wheelchairs but we could not use them". (Beste, F, 42 years old)
>
> "There is a trade dimension in charity. There should be a critical role for the state in charity process. For instance, when an individual wishes to have a school built, there are already determined rules about how it can be done. You provide funds but the state decides how it will be used. There can be similar rules for charity process as well". (Mehmet, M, 38 years old)

While performing charitable activities, givers not only respond to the needs of receivers but also have the opportunity to fulfill and satisfy a series of ethical duties. It seems a win-win situation from givers' perspective because by responding to the needs of unfortunate ones who are the "deserving disabled", problems and needs seem to be addressed as well as competent, powerful and caring image of givers are enhanced. However when behind the scene of this relationship is questioned, there is a deterioration, which further widens the gap between competent non-disabled and needy disabled perception yielding to superiority of helper, and inferiority of protected one.

> "At the political level of charitable action 'damnation' takes two forms: The 'less fortunate' must be cast in the role of the subaltern, neither fully fledged citizens nor fully fledged persons. The generosity embodied in the charitable gift or donation is an attempt to

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[11] It is a nongovernmental organization bearing organization for public weal status

> ameliorate the personal and the socio-political deficits of the ‘unfortunates’. In the act of giving the non-disabled person converts pity into social capital and confirms her status as a benevolent person-citizen who is independent and authentic. There is no reciprocation in the charitable gift; it is a pure act of ‘othering’” (Hughes 2012, p.71)

4.3.6 The Role of Charity in Promoting Normalizing Tendency

In addition to the sharp categorization between disabled and non-disabled people, respondents also attract attention to the gap between “hero disabled” and “unable to be hero yet”. Portraying disabled people as heroes or heroines “despite their impairment” implicitly gives the message that in order to minimize exclusion; disabled people should be like normalized disabled heroes through exceptional performances and charity plays a crucial role in helping the less fortunate ones to succeed. From disabled people’s perspective, there is a connection between the oppression they experience and NGOs’ charity activities.

> “Through charity and the way charity promotes disabled people, the gap between “hero disabled “and “just disabled” is widened more and more”. (Aslı, F, 41 years old)
>
> “Promoting disabled heroes is also very controversial because ideology of “normality” is enhanced through underlining “disabled heroes” are succeeded regardless of social, cultural, economic conditions”. (Aslı, F, 41 years old)
>
> “Charity campaigns enhance the discrimination experienced by disabled people”. (Ali, M, 30 years old)

Last but not the least, this study has revealed that NGOs present charity campaigns as a powerful means to increase personal abilities by enhancing accessibility through providing assistive equipments. However due to instrumental function of passive exclusion (Sen, 2000) arising from language and hidden messages of charity, the outcome of charity results in reduced human capabilities closely related with social circumstances and how disability is perceived in society. Misleading the society and focusing the attention on material needs only, charity activities aim not to challenge the injustices faced by the disabled, but offer temporary, limited and often worsening solutions to the problematic situation on hand, undermining the potential for societal changes and improved awareness in the end. In other words, charity campaigns become a pretext for social exclusionary patterns experienced by disabled people.

CHAPTER 5

CONCLUSION and SOCIAL POLICY DISCUSSIONS

5 Conclusion and Social Policy Discussions

According to the 2002 Disability Survey, disabled people form up to 12.29% of the overall population in Turkey; meaning approximately 1/10th of the population consists of this disadvantaged social group involving people with physical, mental, sensory, intellectual impairments as well as people with chronic illnesses. In spite of representing such a high proportion in the population, disability studies and analysis of disability related concerns and policies are quite new in Turkey. Therefore this thesis has aimed to contribute to a relatively new area of study by analyzing the dynamics of charity, disability and social exclusion relationship in the Turkish context. While this study aims to shed light on the relationship between disability and charity, it is also expected to provide insight into multi dimensional forms of social exclusionary experiences.

Unlike the 2002 Disability Survey, which bases its disability conception on impairment groupings with a medical emphasis, this study acknowledges disability as a multidimensional concept, covering complex interactions between people with impairments and attitudinal as well as environmental barriers. Hence, studying charity targeting disabled people in the Turkish context is believed to reflect how society integrates disability into social and cultural knowledge and how the set of different structural and cultural factors interact with each other in determining disability experience in relation to social exclusion.

The main argument of this thesis is that disabled people as "bivalent collectivities" (Fraser, 1995) experience hybrid forms of exclusionary processes arising from both socioeconomic and cultural representational inequalities and charity is a critical source in worsening these intertwined inequalities and disability oppression. To understand the role and effect of charity and its complex relationship with exclusionary processes, a qualitative research involving in-depth interviews with 16 people with orthopedic disabilities and 7 disability NGOs is employed. The study sample is equally distributed between gender and age intervals of 18-40 and 40+ because gender and age are argued to have significant influence on how disability experience differs between men and women as well as how exclusionary patterns affect disabled people at different age intervals.

Disability has its real meaning and experience in political economy, social and cultural contexts through interaction with other people. Therefore, the political economy, social transformations and cultural understandings have reflections and profound effect on how disability and exclusionary processes are experienced.

The experiences shared by the respondents have shown that people with disabilities have different conceptions about disability from the non-disabled people. For instance, non-disabled people generally tend to consider disability as a physical limitation or a disease, which also reveals itself in frequent daily expressions as “get well soon”. From non-disabled people’s perspective there is a heavy dominance of the medical model of disability whereas the disabled people who participated in this study mostly refer to the social model of disability and underline the role of social, political, attitudinal, physical disabling barriers, prejudices and discriminative society. According to non-disabled people, disability mostly refers to “impairment”, whereas it is a much wider concept with many aspects, which the biased miss out. This differentiation has proven to be an important social-cultural exclusionary factor as disability represents more than being an attribute of an individual. In a sense, disability appears as a marker that encompasses everything which divides the society into two mutually exclusive groups of people as disabled and non-disabled.

Disabled people critically refer to the significance of social and cultural perceptions of disability in discrimination and exclusionary processes that they are experiencing. From their perspective socio-culturally determined devalued roles associated with disability result in “reduced human capabilities” (Sen, 2000). This study shows that socio-cultural exclusion of disabled people involve multifaceted aspects as participants experience broad range of exclusionary practices in their lives. Exclusion from social relations revealing itself through restricted or non-participation in social activities such as segregated areas for disabled people in sport facilities, denying access to education due to incompetent roles, offering under qualified job positions not corresponding to their professional qualifications, being exempt from adulthood through childish attitudes, denying well deserved promotions at work, are to name couple of examples shared by participants. Participants' experiences reflect well that "certain people are systematically devalued and excluded from particular domains simply because they are members of a specific social category or group" (Hutchison P. et al, 2007, p.36). In this process, charity as a two-edged sword is a significant player because of both affecting and affected by social and cultural perceptions of disability.

The charitable dominance in disability is closely related with how society perceives disability. From respondents' perspective, the society through equalizing disability to impairment constrains people with disabilities with particular social roles, which reflect societal expectations about how disabled people should live, what they need. Accordingly, without exception each respondent regardless of gender and age variables state that disabled people are seen as destitute, useless, unnecessary, disrespectful, pitiful, incomplete and dependent individuals by the society. From societal perspective they "need help" to manage their life and charity seems a useful way to do it.

Diverse forms of exclusionary experiences are shared by disabled people who participated in this study. Some are quite commonly shared among the vast majority of the disabled population such as restricted opportunities because of low societal expectations questioning capability of disabled individuals. Some, though, are determined and vary by gender and age.

In this study, while female respondents mostly focused on being exposed to childish attitudes, differentiated gender roles and exclusion in education etc, male respondents mostly attracted attention on dependency creating circumstances, barriers related with participation into social life and the precluding role of disability. The emphasis on exclusion in education commonly voiced by women participants is also consistent with the data provided in 2002 Disability Survey. Accordingly, both the illiteracy rate and the education level of disabled women are significantly lower than disabled men in each impairment groups including orthopedic disability in 2002 Disability Survey. “Disability and gender factors also interact and have an additional adverse influence on educational opportunities. More than 51% of disabled females are illiterate, compared with approximately 26% of disabled males” (Tufan I., Yaman E., 2007) This situation can be interpreted as a reflection of constraining women within traditionally defined gender roles not necessitating educational achievements. Traditionally women are seen as care givers, mothers, wives…etc. and they are mostly assessed according to their capacity to perform such roles. Their primary responsibility is defined in private sphere of the household and they are expected to perform well about socially constructed women associated roles. However commonly voiced childish attitudes and emotional exclusion in this study show that disabled women not only experience barriers to access education due to gender roles and disability but also experience emotional exclusion due to low expectations about their performances as wives, mothers and caregivers, as they are seen exempt from gender roles. The experiences of disabled women in this study confirm the argument of Abu Habib (1995, p.51) stating “the rights to marriage, to sexual and reproductive rights, and to family life are often implicitly denied to disabled women on the basis that disability has deprived them of their sexuality and they can therefore no longer fulfill the roles of sexual partner, mother and carer”. Social and cultural understandings of disability are powerful sources in above explained exclusionary experiences and become a source in disability oppression as well.

Older people with disabilities are even a more disadvantaged group, as disability is much more easily associated with -and considered as an outcome of- old age. This study reveals that disabled people become more vulnerable as they get older because of reduced mobility expectations that affect the degree of socialization and access to informal support mechanisms. The priorities set by NGOs privileging young ones also confirm these concerns. The frequent emphasis on being alone and inability to satisfy financial worries at older ages; underline increased exclusion risks and vulnerability. In addition to disability, this study shows that age discrimination creates further vulnerability in terms of material deprivation as well as in affording extra costs associated with disability. Hence, as confirmed by older participants’ experiences, governmental supports and legislative framework regulating social policies and entitlements have a crucial role for older disabled people to remain independent. For that reason, the social policy instruments should be revised to acknowledge the possible exclusion risks and concerns of older disabled people. To prevent further exclusion risks related with age, it is also important to conduct other studies focusing on experiences of older disabled people.

In line with Morris' (2001) arguments social policy discussions often overlook the ends because of too much focusing on the means. Establishing proper social policies as well as revising and evaluating existing ones requires comprehensive analysis of target groups that social policy instruments aim to address. Hence statistical data and descriptive statistical analysis involving sociodemographic, socioeconomic characteristics, expectations, problems, regional differences etc. are key features to have a better understanding. Turkey's most comprehensive and recent statistical data related with people with disabilities dates back to 2002, which results in a shortcoming about available statistical information and analysis. Even this inadequacy can be interpreted as disability being a low priority issue at the state level agenda. To have a better understanding about the current situation regarding disability in Turkey, it is necessary to conduct a well-designed statistical survey by Turkish Statistical Institute in cooperation with the Ministry of Family and Social Policy and universities competent in the field of disability research.

Defining disability is also problematical in the 2002 Disability Survey. Accordingly, the definition of disability had strong references to normality with impairment based groupings and functional limitations. Until the recent amendment in 2014, defining disability had a strong medical dominance in the legislative framework as well. Furthermore despite the recent amendment in the Law on Disabled People adopting a strong social model emphasis in defining disability, this study reveals that still this amendment could not have been reflected in the administrative categorization and definitions of disability. Yet for social policy instruments, identifying who belongs to the disability category and who does not, has its roots from medical view of disability through increased scrutiny and control of health professionals. This hypocrisy reflects well the strong legislative driven approach without a proper implementation in the field of disability which results in trust issues between the state and its disabled citizens.

This study reveals that society has very low expectations as far as disability is concerned. Low expectations about disabled people not only affect “reduced human capabilities” (Sen, 2000) but also result in disabled people’s endless efforts to prove themselves and make society reconsider that disabled people are better than what people already think. Although some of the studies cited in (Hutchison P., Abrams D. and Christian J., 2007) show that group based exclusion and discrimination can result in the mobilization of group members through collective action to resist and overcome the group’s exclusionary status, in the Turkish context individualized actions predominate. As a response to low societal expectations, people with disabilities emphasize individualized efforts rather than collective actions that can challenge negative connotations associated with disability. As a result, instead of challenging the role of social and cultural understandings of disability in disability oppression through collective efforts, disabled people tend to tackle disability oppression at individual level.

When people with disabilities finally perform beyond societal expectations, non-disabled people instead of breaking down their prejudices about disability, heroize the successful ones and still continue to hold their prejudiced attitudes against the rest of the disabled population. Respondents described this tendency as hypocrisy on many occasions.

Although disability activism is one of the key features to challenge societal hypocrisy as well as social and cultural understandings of disability, the individualization tendency and distancing of disabled people from disability identity because of grouping disabled people under two mutually exclusive groups as victims and those refusing to be victims, are two important barriers that hinder the motivation of disabled people as a political movement.

As low societal expectations about disability are referred as one of the most important sources behind exclusionary processes experienced by disabled people, efforts to deconstruct meanings attached to disability and transform the way disabled people are perceived, require comprehensive awareness raising programs and policies managed by the Ministry of Family and Social Policy in cooperation with the rights based disability NGOs.

Similar to disabled individuals' emphasis on individualized efforts in tackling exclusionary processes, this study reveals that the state policy in addressing its disabled citizens also promotes individualization of disability oppression. In line with previous studies discussing social policy in Turkey (Çelik, 2010, Bezmez &Yardımcı, 2010, Buğra & Keyder, 2006, Buğra 2012), this study confirms that conservative benevolence emphasizing individual centered approach has started to replace social state and its instruments in Turkey. Accordingly, except one of the interviewed NGOs, all of them have been contacted by the state institutions, to address the needs of disabled individuals in an individualized manner. Hence a charity system incorporated into state institutions is created. Through this system, personal requests of disabled individuals submitted to politicians, politically powerful parties and ministers are formalized and met privately. The charity system by using disability related NGOs as subcontractors makes them become critical structural players and further enhances individualization of disability oppression by affirmative remedies disguising inequality-creating processes.

Although the state's passive engagement through charity system incorporated into state institutions aims and seems to ease economic burden on the state and provide political gains, as a matter of fact the political mobilization among disabled people is hampered through individualization of oppression. The lack of a conscious and organized disability movement at the same time prevents a strong field experience that can be provided by disabled people and their organizations with regard to the future and ongoing legislative efforts.

The neoliberal transformation has not helped, instead worsened the disadvantage creating processes for disabled people by justifying state's passive engagement. Respondents critically refer to "state charity" and state's inability to respond to the needs of its disabled citizens via a national disability policy based on citizenship rights. The trust issues between the state and disabled people are identified as a result of ineffective implementation of legislation as well as legislative efforts involving discriminative provisions among disabled people.

The selective treatment giving a group of disabled people privileged position over others through discriminative provisions especially with regard to healthcare expenses inevitably becomes a source of exclusion for those who frequently incur such expenses. This discriminative understanding is not only against equality but also raises the question of whether some disabled individuals are more equal than others. Therefore to ensure equality both before the law as well as in practice, it is important to identify all discriminative provisions in the legislative framework and amend them according to categorical universality.

Legislative categorization adopting a medical dominance unable to take environmental factors into account in evaluating disability and one size fits for all approach still persists in Turkey. Strict administrative categorization of disability is a critical exclusionary source because of leaving people with orthopedic disabilities alone in meeting their needs associated with disability. Participants commonly voice that assistive equipments are indispensable necessities in their lives and they strongly criticized the Communiqué on Health Implementation due to its standardized, inflexible and unrealistic pricing policy unable to respond to the heterogeneous personal needs. The healthcare and assistive device needs of disabled people despite being medically reported as necessary, are barely satisfied due to uniform understanding of SUT. The high costs associated with healthcare expenses and assistive device needs urge disabled people to meet their needs through informal mechanisms or depend on families or deny access leading to restricted participation into social life. Therefore, as this study reveals to address exclusionary processes arising from legislative framework, social policy instruments as SUT, needs to be revised to challenge uniform approaches that violate the rights of disabled people. With respect to legislative amendments, receiving suggestions and perspectives of relevant parties with the field experience and expertise are of vital importance. Both the Ministry of Family and Social Policy as being the responsible organization of elderly and disabled and the rights based disability NGOs with expertise should be involved in advising and guiding legislation amendment processes.

From disabled people’s perspective, strict conditionality requiring proof of extreme poverty through strict means testing as well as medical evaluation of disability to limit target group and to ease the economic and institutional burden of disabled people on the state, are reflections of hypocritical processes managed by the state. One of the respondents’ quote summarize well the situation with regard to the state’s perspective. “State on one hand entitles rights and privileges to disabled people but on the other hand it makes an effort to restrict those rights” (Can, M, 48 years old).

Strict categorical eligibility adopting household scale analysis for means testing reveals that disabled people rather than being considered as equal citizens are seen as dependent family members. Social policy schemes to a great extent are outcomes of this distorted perception. In Turkey it is not possible to combine governmental supports such as disability and home care allowances and other income generating activities. The strict conditionality affects people with disabilities to obtain decent level of income responding to the realities in their life. Accordingly, neither disability allowances nor their income is solitarily enough to afford incurred expenses. This study shows that exclusionary processes experienced by disabled people are closely related with legislative efforts unable to satisfy categorical universality for disability.

From above pictured framework, charity becomes a more beneficial and easy substitute than entitlements provided by governments. The state’s profit-oriented perspective regarding its disability policy is very significant in determining the dominance of charity in disability. Due to exclusionary process arising from a profit-oriented perspective, it is advised to adopt a categorical universality for social policy instruments targeting disabled citizens. Abandoning the household scale analysis for means testing and determining the amount of monthly allowances by taking the realities of disabled people’s lives into account are equally important in addressing exclusionary processes.

The medicalization tendency with regard to disability is very influential in social exclusion experienced by disabled people because it has direct effect on determining legislative categorization of disability and capabilities. Medical reports assessing the extent of disability appears as the first and most important step from both perspective of the state and NGOs in order to be “legally” considered as disabled. However, medical reports are rarely reliable, according to respondents. They are in doubt about the objectivity of reports and state that each hospital and doctor may provide different reports, which severely undermines equality. Moreover the significance of medical view in defining who is disabled and to what extent emphasizes functional limitations and underestimates social aspects and environmental factors. This tendency is worsened by the formation of committee examining disability reports that solely involves health specialists with medical background. Although medical specialists are not the ones who personally experience impairment and social and environmental barriers, their decisions of what is best for disabled people directly affect those who experience impairment everyday in their lives. To acknowledge complexity of disability depending on the context, committees examining disability reports should also involve social workers, NGO representatives. Also, in some cases, these reports appear as a control mechanism the state has established. In a sense what is provided through legislation is taken back by its restricted implementation through strict financial and medical control and scrutiny exercised by professionals.

In this study, disability related NGOs are determined as one the most critical players in the dynamic relationship between disability, charity and social exclusion. Interviewing disability NGOs has primarily shown that there is confusion about the roles and responsibilities between the state and NGOs and this confusion affect how NGOs set priorities and manage their activities and relationship with disabled people. Despite the grand narratives such as “advocating equality for all” and “rights based approach to disability”, the main priority of interviewed NGOs centers on fund raising, charity and literally “helping” disabled individuals. The relationship between NGOs and disabled people is dominantly defined through “need” and “satisfaction of personal needs”. This tendency is closely related with but not limited to NGOs preference about marketing themselves as help centers for satisfying their target audience and self-survival. Also, state institutions and municipalities through their individualized requests from NGOs, promote the dominance of charity within NGO activities. However NGOs prioritizing charity activities as the first and only concern in their agenda is widely criticized by respondents and cited as an important feature to distance themselves from NGOs. According to disabled people, the efforts of

NGOs contribute to legitimate unmet liabilities of the state and enhance perceptional misunderstanding about disability.

The close relations between NGOs and the state have some respondents in doubt as well. Maintaining the titles “association for the public weal” and “authorized association to fund raise without permission of related state authority” is vital for NGOs as they rarely refer to membership fees as a financial source and depend on donations. The strong patronage relationship between the state and NGOs make them act as satellites of the state institutions through satisfying their part in charity based social policy system. Instead of mobilizing and promoting disability as a political issue, remaining silent and avoiding activism give better results either for preserving already granted privileged status or for securing one. Accordingly, the strong patronage relationship between the state and NGOs prevent the latter becoming rights based organizations, which results in weak influence of disability NGOs in reflecting priorities of disabled people as well as a lack of expertise in the field of disability when needed.

From disabled people’s perspective NGOs, instead of promoting activism questioning disabling barriers and transform conventional attitudes, adopt medicalization and privatization of disability, which work better to secure more support and donations from the society as well as to secure privileged status granted by the state.

This study reveals that people with disabilities as cultural agents through promoting or challenging victimization associated with disability play a crucial role in shaping the significance of charity in disability. People with disabilities who make use of their impairment and allow NGOs to exploit disability are strongly criticized because of being the main source of popularity and continuity of charity campaigns. Additionally, respondents’ disapproval about the incompetent, victim role played by majority of disabled people results in distancing themselves from disability identity. Similar to societal response upgrading disabled people to non-disabled category upon performances beyond expectations, respondents in this study also act in a similar way and prefer disassociating themselves with disability due to the majority of disabled people who internalize victimization. A strong emphasis on individualized efforts by performing beyond expectations together with distancing from disability identity appear as two important obstacles preventing disabled individuals' involvement in disability movement.

Within the scope of this thesis, strong patronage relations between the state, disability NGOs and disabled individuals have influence on exclusionary processes experienced by disabled people through individualization of oppression and discouragement of disabled individuals as cultural agents. The existence of strong rights based NGOs are not only crucial for assisting comprehensive policy making processes but also for reflecting priorities of disabled people in NGOs' agenda as well as in the state policy.

Disabled individuals' unawareness about the national and international laws as well as their rights hinder political mobilization of an organized and conscious disability movement gathered around shared cause. Therefore it is necessary for the Ministry of Family and Social Policy to inform disabled people about the developments in national and international laws related with disability. Proper information channels accessible for all disabled people play a crucial role as well. The Ministry of Family and Social Policy should take leading role in this process.

The charity culture finds its roots in the aforementioned complex and intertwined exclusionary processes. Charity, as being a more beneficial and easy substitute than social policy instruments provided by the government, at the same time ‟becomes a necessity in the context of an unequal and disabling society" (Shakespeare, 2000, p.55) and both affected by and worsens prejudiced social perceptions about disability.

Once being a major political ground to mobilize disabled people by voicing the slogan of ‟rights not charity", charity activities in the Turkish context play a crucial role in undermining collective actions instead. One of the most important conclusions of the study is that charity appears both as a "source "of social-cultural exclusion and an "outcome" of economic-structural exclusion experienced by disabled people. Furthermore it is concluded that charity activities worsen the socio-cultural exclusionary processes experienced by disabled people by promoting strong dualism pointing two mutually exclusive groups of people as disabled and non-disabled. It is also observed that promoting charity as the major solution to the problems of disabled people disguises the root causes of exclusionary processes and distances disable people from disability related NGOs and undermines disability activism.

By centering on “help us to help them” message, charity creates social oppressive relations. Rather than making non-disabled people question their role in disablement, an easy option of “donate and get rid of your responsibilities” is offered. Another critical feature with regard to the charity is that it also defines its deserving criteria, which also result in exclusionary patterns where a great portion of disabled people is further excluded based on age discrimination to a great extent.

As part of this study, the ubiquitous use of wheelchairs in charity campaigns not only result in society to overemphasize material deprivation of a particular disability group over other sources of inequalities but also reinforce certain kind of impairments to dominate disability experience and ignore other forms of disability. Charity with its controversial nature both serving as a positive value by addressing deprivation on the one hand and serving as a mechanism of social oppression on the other hand ruins what has been repaired.

Charity activities are identified as important sources of oppression for disabled people because of problematic representations, language, visuals and discourses it employs. For that reason, efficient monitoring and control by the state authority is indispensable with regard to the authorship of charities in the cultural representation of disability. Moreover the messages, language and visuals employed by charity campaigns evoke pity and reinforce ableist standpoint equalizing disability with inability and helplessness.

Cultural meanings attached to disability that involves cultural codes and expected roles about disabled individuals are closely related with media representation, language and portrayal of disability in curriculums and become significant sources in socio-cultural exclusion. As Harpur (2012) also underlines “language is a powerful tool in influencing how society and culture constructs disabilities”. To avoid media and curriculum mediated disability stereotypes and to avoid non-disabled people's subjectivity evoking fear and pity, the Ministry of Family and Social Policy should prepare media guidelines for the portrayal of disability. While doing so, the Ministry should work in close cooperation with the rights based disability NGOs and avoid portraying disabled people either as victims or exceptional heroes. Promoting disability as a common human experience can challenge prejudices and exclusionary patterns related with stereotyped portrayal of disability. The establishment of a unit under the governance of the Ministry of Family and Social Policy and the Ministry of National Education that is responsible of revising curricula and stereotyped portrayal of disability in the curricula is considered as necessary.

Lastly, as this study clearly reveals, unless the fight against cultural constructionist approaches to disability is ensured, legislative efforts are somehow palliative and reinforce dualism dividing the society into two mutually exclusive groups of people as disabled and non-disabled. Disabling barriers, either be rooted in socioeconomic or socio-cultural representational inequalities, can be addressed by joint and coherent policies designed and implemented by the cooperation of the state, society, disability NGOs and disabled people as active cultural agents.

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APPENDICES

APPENDIX A

PROFILE OF INTERVIEWED DISABILITY NGOs

	Date of Establishment	Scope	NGO for Public Weal Status	Number of Members	Number of Disabled Executive Board Members	Target Group	Main Activities	Charity Activities and means of Fund Raising	Requirements and Main Criteria for Charity
NGO 1	1998	To address problems of people with orthopedic disabilities regarding medical, vocational, economic and social issues and prevent further disability and perform awareness raising activities	YES	2500 (official)	3	People with Orthopedic disabilities	Charity activities, vocational training, legal, social and medical services, awareness raising	Assistive device distribution-battery powered wheelchair campaign. Financed through: donations, blue lid campaign, telethon, sms campaigns	Medical report, certificate of poverty, assessment of social security status, petition of applicant, physical condition of applicant, age (priority given to students and young applicants) Selection made by science and advisory board + social assessment system, priority given to earlier applications
NGO 2	2010	To serve and help people with orthopedic disabilities regarding their needs and problems	NO	362 official (appx. 8000 unofficial)	4 (out of 7 members)	People with Orthopedic disabilities	Vocational training, physical therapy and rehabilitation, charity activities	Mediating role in charity activities, assistive device distribution. Financed through: Donations and income through sales of handcraft	Medical report, financial and physical assessment of applicant, age (priority given to students and young applicants) Selection made by science board+ informal social assessment system

	Date of Establishment	Scope	NGO for Public Weal Status	Number of Members	Number of Disabled Executive Board Members	Target Group	Main Activities	Charity Activities and means of Fund Raising	Requirements and Main Criteria for Charity
NGO 3	1993	To provide assistance for people with disabilities regarding health and educational needs and to enhance active and equal participation into social life.	YES	5000 (official)	3	People with disabilities (without an emphasis on a particular type of impairment)	Charity activities and organizing social activities	Charity activities for health operations and educational needs. Assistive device distribution. Financed through: Donations	Medical report and assessment of financial situation of applicant Selection made by executive board following an informal social assessment system
NGO 4	1991	To guide, socialize and motivate people with disabilities	YES	2356 (official)	7 (out of 9 members)	People with Orthopedic disabilities	Charity activities and establishment of a large scale segregated housing project and recreational facility for disabled people and organizing social activities	Charity activities for assistive device distribution. Financed through: Donations, blue lid campaign.	Membership requirement, medical report and assessment of financial situation of applicant, age (priority given to students and young applicants) Selection made by informal social assessment system
NGO 5	1960	To fight against major causes (car and work accidents, health policy, terror, kin marriage) of disability and prevent disability, protect and further enhance economic, cultural, social and vocational etc. rights of disabled people, combat against discriminative provisions and implementations	YES	127.000 (official)	All executive board members are disabled	Particularly people with orthopedic disabilities but people with other type of impairments are also among target group	Charity activities regarding health and education, vocational training, social and physical therapy, rehabilitation and promotion of sportive activities	Charity activities for assistive device distribution. Financed through: Donations, membership fees, estate income, revenues from social activities	Medical report and assessment of social security status, petition of applicant, age (priority given to students and young applicants) Selection made by executive board following an informal social assessment system

	Date of Establishment	Scope	NGO for Public Weal Status	Number of Members	Number of Disabled Executive Board Members	Target Group	Main Activities	Charity Activities and means of Fund Raising	Requirements and Main Criteria for Charity
NGO 6	1998	To represent disabled people, to voice people with disabilities' problems, create public opinion and awareness about disability. To enable disabled people's equal participation into live (before 2001 charity activities to meet individual needs and requests)	NO	approximately 3000 registered member (unofficial)	1 (out of 3 members)	People with physical, visually, hearing, mentally impairment and chronic illness (%40 and above)	Rights based awareness raising activities and charity activities (assistive device distributing campaigns+ assistance for health operation expenses), assistance during job seeking	Charity activities for health operations and assistive device distribution Financed through: Donations, SMS campaigns, telethon	Medical report, financial assessment of applicant, certificate of poverty, age (priority given to students and young applicants) Selection made by science board
NGO 7	1995	To guide and help people with disabilities mainly through education (segregated) and rehabilitation	YES	130	1 (out of 7 members)	Particularly People with Orthopedic and Mental Disabilities but people with other impairments are also among target group	Charity activities, physical therapy and rehabilitation as well as educational activities	Charity activities for assistive device distribution. Financed through: Estate income, donations	Medical report, letter of undertaking, age (priority given to students and young applicants) Selection made by executive board following an informal social assessment

APPENDIX B

ENGAGEMENT DOCUMENT

(TAAHHÜTNAME)

Ben (Gizem Girişmen) Orta Doğu Teknik Üniversitesi Sosyal Politika Yüksek Lisans Programı'nda **"Devlet ve Sivil Toplum Kuruluşlarının Engellilik Hakkındaki Sosyal ve Kültürel Anlayışlarının Yansımaları : Sosyal Dışlanma Dinamikleri"** başlıklı tez çalışmam çerçevesinde .... tarihinde .... ile gerçekleştirdiğim mülakatın çıktılarını sadece bilimsel amaç ve yöntemlerle kullanacağımı, ……………….................................'ın kimliğini ortaya çıkaracak alıntılar yapmayacağımı ve adını hiçbir yerde geçirmeyeceğimi, aksi halde doğacak maddi ve manevi zararın tarafıma ait olduğunu ve cezai yükümlülükleri kabul ettiğimi taahhüt ederim.

Gizem GİRİŞMEN

APPENDIX C

INTERVIEW QUESTIONS

Görüşme No:	
Tarih:	
Başlangıç Saati:	
Bitiş Saati:	

1. Kişisel Bilgiler

1.1 Cinsiyet:
1.2 Yaş:
1.3 Doğum yeri:
1.4 Medeni Durumu:
1.5 Engel durumu, türü (doğuştan, sonradan, hangi engel grubunda olduğu):
1.6 Engel yüzdesi (bugüne kadar aldığı raporlarda engel yüzdesinde değişiklik meydana gelip gelmediği, değişiklik olduysa sebebi):
1.7 Engelli raporları ile ilgili ne düşünüyorsunuz? Engellilerin hayatında ne gibi bir yeri var?
1.8 İhtiyaç duyulan yardımcı cihazlar ve cihazlara erişim durumu:
1.9 Karşılayamadığınız ihtiyacınız var mı? Varsa ne şekilde çözmeye çalışıyorsunuz?
1.10 Eğitim durumu (en son diploma alınan okul):
1.11 Meslek:
1.12 Sosyal güvenceniz var mı?
1.13 Çalışma deneyimi-İş arama girişimi:
1.14 Gelir durumu: (Türkiye şartlarına göre nasıl değerlendiriyorsunuz)
1.15 Maddi desteğe, yardıma ihtiyaç duyuyor musunuz? Evet ise ihtiyaç duyduğunuz desteği, yardımı alabiliyor musunuz? Nereden?
1.16 STK'lardan veya devletten aldığınız maddi/ayni destek var mı? (Varsa süreç ve fikirleri)

2. Aileye ilişkin bilgiler

2.1 Anneniz ve babanız hayatta mı? Ne iş yapıyorlar? / Evli ise eşiniz hayatta mı? Ne iş yapıyor?
2.2 Eğitim durumları?

2.3 Ailenizle birlikte mi yaşıyorsunuz? Ailenizle yaşadığınız için daha mutlu ve güvende hissediyorsunuz musunuz?
2.4 Ailenizin maddi imkânlarını nasıl değerlendiriyorsunuz? Sizce yeterli mi? Türkiye şartlarına göre değerlendirir misiniz?

3. Engellilik Olgusuna Bakış

3.1 Sizce engelli kim?
3.2 Türkiye'de engelli nüfusu sizce ne kadardır?
3.3 Engelliler toplumda nasıl değerlendiriliyor? Nasıl tanımlanıyor?
3.4 Sizce engellilere haksızlık ediliyor mu?
3.5 Engelli insanlar ülke için sıkıntı yaratır mı? Toplumun bu konudaki bakışı nasıl sizce?
3.6 Engelli diyince aklınıza ilk hangi engel grubu geliyor? Sizce aklınıza neden ilk bu grup geldi?
3.7 (Görüşme sırasında normal kelimesi kullanıldığı takdirde sorulacak) Sizce normal kim? Normal olmayı tanımlar mısınız? -
3.8 Engeliniz hayatınızı etkiliyor mu: Evet ise hayatınızda neleri etkiliyor, ne tür sıkıntılar yaşıyorsunuz?
3.9 Diğer engellilerin yaşadığı sıkıntılar neler olabilir? Engellilerin eğitim, iş, sosyal hayata katılımı konusunda ne düşünüyorsunuz?
3.10 Engeliniz dolayısıyla eleştiri aldığınız oldu mu? Ya da övgü aldığınız?
3.11 Sizce engellilerin en büyük sorunu ne? Yaşanılan sıkıntılar engel gruplarına göre değişiklik gösteriyor mu?
3.12 Sizce engelli olmak toplumdaki beklentilerde bir farklılık yaratıyor mu? Beklentiler engelli olmasaydınız farklı olur muydu?
3.13 Engelliler doğrudan veya dolaylı ayrımcılığa maruz kalıyor mu? Evet ise sizin bu konuda bir deneyiminiz oldu mu?
3.14 Engellilere yeterince imkân veriliyor mu?
3.15 Toplum tarafından anlaşılmadığınızı düşünüyor musunuz? Evet ise düzeltmek için ne yapılmalı?
3.16 Kendinizi dışlanmış hissettiğiniz oluyor mu?
3.17 Hayatınızla ilgili kararları nasıl alıyorsunuz?
3.18 Hayatınız boyunca yaşadığınız iyi ve kötü olayları değerlendirdiğinizde engelli olmanızı bu değerlendirmenin neresinde konumlandırırsınız?
3.19 Sizce engelli olmak üzücü mü? Evet/Hayır ise neden
3.20 Engelli bir birey oluşunuzun, size gösterilen saygıda ya da duygu ve düşüncelerinizin dikkate alınmasında/alınmaması etkili olduğunu düşünüyor musunuz?
3.21 Bir engelli nasıl yaşamalı? Nasıl bir hayatı olmalı?
3.22 Çevrenize baktığınızda kimin yerinde olmak istemezsiniz?
3.23 Gelecek 10 yıl içinde kendinizi nerede görüyorsunuz?

3.24 “Bir gün herkes engelli olabilir” söylemi ile ilgili ne düşünüyorsunuz? Sizce etkili bir söylem mi?
3.25 “Hepimiz engelli adayıyız” söylemi ile ilgili ne düşünüyorsunuz? Engelli bireylerin yaşadığı sıkıntıları çözmek adına etkili bir yaklaşım mı?
3.26 “Geçmiş olsun” söylemi ile sıkça karşılaşıyor musunuz?
3.27 Size, “Sen hiç engelli gibi değilsin,” dendiğinde ne hissedersiniz?
3.28 Sizce toplumun engelliye bakışı diğer ülkelerde değişiyor mu yoksa her yerde aynı mı?
3.29 Toplumun engelli bireylere karşı bir sorumluluğu var mı? Varsa nelerdir?
3.30 Engelli bireylerin neye ihtiyacı olabileceği sorulduğunda, engelli olmayanların aklına ilk ne geliyor? Sizce neden?
3.31 Engelli bireylerin vatandaş olarak sorumlulukları var mı? Varsa nelerdir?
3.32 Aynı toplumun parçası olarak sizin, engelli olmayan bir bireyden beklentileriniz ne?

4. Türkiye’de Engelliler ile ilgili STK’lara Bakış

4.1 STK(lar)da üyeliğiniz var mı? Evet ise ne zamandan beri? Hangi STK(lar)? Niçin o kuruluşlara üye olmayı istediniz? Aktif bir göreviniz var mı? Hayır ise neden üyeliğiniz yok?
4.2 Derneklerin bir yararını veya zararını gördünüz mü?
4.3 Engelli dernekleri dediğimde aklınıza ne gibi faaliyetler geliyor?
4.4 Türkiye’de engelliler ile ilgili çalışan STKları nasıl değerlendiriyorsunuz? Yönetim anlayışlarını, engelliliğe bakışlarını, söylemlerini, proje fikirlerini ve uygulamalarını nasıl buluyorsunuz? Örnek verebilir misiniz?
4.5 Engelliler ile ilgili yapılan yardım kampanyalarında STK’ların rolü sizce ne?
4.6 Sizce engelliler ile ilgili çalışan STK’lar veya dernekler engelliler tarafından mı yönetiliyor? Yönetilmesi veya yönetilmemesi bir fark yaratır mı?
4.7 Engelliler ile ilgili çalışan bir STK’dan beklentileriniz neler? Sizde güven uyandırıyor mu? Ürettikleri projeler etkili mi?
4.8 Yardım kampanyası odaklı derneklerin hak temelli derneklerden daha bilinir, görünür ve kaynak açısından daha zengin olduğunu düşünüyor musunuz? Daha fazla mı destek görüyorlar?
4.9 Bazı insanlar artık derneklerin engelliler tarafından yönetildiğini ve derneklerin geçmişteki negatif imajının artık geçerli olmadığını iddia ediyor. Katılıyor musunuz?
4.10 Türkiye’de engelliler ile ilgili çalışan derneklere ilişkin gelecekteki beklenti ve görüşleriniz nelerdir?

5. Engelliler ile ilgili Yardım Kampanyalarına Bakış

5.1 Engellilerle ilgili yardım kampanyası dendiğinde aklınıza ilk gelenler, ilk hatırladıklarınız nelerdir? Nasıl değerlendiriyorsunuz bu kampanyaları? Etkili mi?
5.2 Hiç engellilerle ilgili bir yardım kampanyasına katıldınız mı? Neden?
5.3 Hiç genel anlamda bir yardım kampanyasına katıldınız mı? Neden?
5.4 Sizce yardım kampanyalarının engellilerin yaşamlarına nasıl etkileri var?
5.5 Sizce yardım kampanyaları neden bu kadar ön planda?
5.6 Yardım kampanyaları kapsamında engelliler ile ilgili yapılan projeleri nasıl buluyorsunuz? (ör: Çevre ve Şehircilik Bakanlığının temiz çevre engelsiz yaşam kampanyası, mavi kapak toplama, Adım Adım oluşumu-maraton koşusu- aralarında sizce bir fark var mı?)
5.7 Bu tarz kampanyaların etkili olduğunu, amacına ulaştığını ve engellilerin sorunlarına çözüm ürettiğini düşünüyor musunuz?
5.8 Engellilerin ihtiyaç duyduğu tekerlekli sandalye, akülü tekerlekli sandalye, yürüteç, görme engelliler için baston vs. yardımcı malzemelerin yardım kampanyaları aracılığı ile verilmesi hakkında ne düşünüyorsunuz?
5.9 Engelliler ihtiyaç duydukları yardımcı cihazları edinirken sıkıntı yaşıyor mu? Bilginiz veya fikriniz var mı? Sizce devletin bu noktada rolü ne olmalı?
5.10 Yardım kampanyaları toplumun engellilik algısına nasıl etki ediyor sizce?
5.11 Yardım kampanyalarının yapısı ve bu kampanyaları düzenleyen kuruluşlar ile ilgili ne düşünüyorsunuz? Yönetim anlayışları, projeleri, kullanılan görseller, amaçlar vb.
5.12 Bu tür yardım kampanyalarının, devletin üzerinde olması gereken bazı sorumlulukları ve yükleri hafiflettiğini düşünüyor musunuz? Böyle olmalı mıdır?
5.13 Sizce engelli olmayan bireyler yardım kampanyaları hakkında ne düşünüyor? Neden bu kampanyalar bu kadar ilgi görüyor?
5.14 Sizce engellilerin yardım kampanyalarına ilişkin ortak bir görüşü ve duruşu var mı?
5.15 Sizce yardım kampanyaları engellilerin eğitim, iş, ulaşım, sosyal hayata katılım gibi konularda yaşadıkları olumsuzluklara olumlu veya olumsuz katkı sağlıyor mu?
5.16 Sizce yardım kampanyaları, engellilerin hak eksenli taleplerini etkiliyor mu? Siyasi girişimlerin ve taleplerin toplum nezdinde daha görünüp bilinir olmasını etkiliyor mu?
5.17 Yardım kampanyaları engelli politikalarının bir parçası olmalı mı?
5.18 Sizce, engelli bireylerin erişilebilirlik, eğitim, istihdam vs. ile ilgili karşılaştıkları sıkıntılar ortadan kalksa yardım kampanyalarına yine de ihtiyaç olur muydu?

5.19 Sizce asıl amaç yardım toplamak mı yoksa yardım etmek mi? Bu kadar kesin bir ayrım yapmak kolay mı? Güven duyuyor musunuz?
5.20 Dünyada engelli hakları hareketinde yardım kampanyalarına karşı başlatılan protestonun önemli bir etkisi olmuş, sizce Türkiye'de de yardım kampanyaları hak talep eden böyle bir karşı duruşa yol açar mı?

6. Engellilerin Temsiline ilişkin Görüşler

6.1 Engellilerin görsel ve yazılı medyadaki temsilini yeterli buluyor musunuz? Neden?
6.2 Siz veya çevrenizden medyada yer alan oldu mu? Bir habere konu oldunuz mu?
6.3 Takip ettiğiniz kadarıyla medyada engellilerin yer aldığı haberlerin içeriklerini, sunumlarını, söylemlerini nasıl buluyorsunuz? Gerçeğin doğru ve güvenilir biçimde yansıtıldığına inanıyor musunuz?
6.4 Engellilere ilişkin medyada yer alan haberler sizce nasıl olmalı?
6.5 Engellilerin medyada temsiline ilişkin bir iyileştirme yapmak için görevlendirilseniz nereden başlarsınız?

7. Devletin Engelliler ile ilgili Politikası ve Kurumsal Desteklere İlişkin Görüşler

7.1 Yürürlükte olan engelliler kanunu biliyor musunuz? En son ne zaman değiştiğini ve ne gibi değişiklikler getirdiğinden haberdar mısınız?
7.2 Bu kanun kapsamında kime engelli deniyor?
7.3 Ne gibi kanuni haklarınız, muafiyetleriniz var?
7.4 Devletin sağladığı desteklerden haberdar mısınız? Nasıl değerlendiriyorsunuz?
7.5 Engellilerin ihtiyaç duyduğu yardımcı malzemelerin(tekerlekli sandalye, baston, işitme cihazı vs.) edinilme kurallarını ve devlet katkısını içeren Sağlık Uygulama Tebliği'nden haberdar mısınız? Bu tebliğ ile ilgili ne düşünüyorsunuz?
7.6 Türkiye'nin de taraf olduğu BM Engelli Hakları Sözleşmesi ile ilgili bilginiz var mı? Türkiye'nin bu konuda yerine getirmesi gereken yükümlülükleri biliyor musunuz?
7.7 Türkiye'de engelli politikasının geleceğine ilişkin beklenti ve görüşleriniz nelerdir?
7.8 Devletten neler bekliyorsunuz?

APPENDIX D

TÜRKÇE ÖZET/ TURKISH SUMMARY

DEVLET VE SİVİL TOPLUM KURULUŞLARININ ENGELLİLİK HAKKINDAKİ SOSYAL VE KÜLTÜREL ANLAYIŞLARININ YANSIMALARI: SOSYAL DIŞLANMA DİNAMİKLERİ

Bu tez, Türkiye'de yardım kampanyalarının ve muhtaçlık ekseninde yardım anlayışıyla şekillenen sosyal politikaların, sosyal dışlanma ve engellilikle ilintili rolünün yanı sıra engellilere yönelik gerçekleştirilen yardım etkinliklerinin ardındaki yapısal ve kültürel etmenleri incelemeyi amaçlamaktadır. Çalışma kapsamında sosyal dışlanmanın, bir durum tespiti olmaktan çok, çok boyutlu bir süreç olarak hem ekonomik-yapısal dışlanma hem de sosyo-kültürel dışlanma kavramlarını kapsadığı kabul edilmektedir.

Engelli bireylerin hem sosyoekonomik hem de kültürel temsilinden kaynaklanan eşitsizlikler sebebiyle çok yönlü dışlayıcı süreçlere maruz kaldığı, yardım kampanyalarının ve muhtaçlık ekseninde şekillenen politikaların bu süreçleri daha da kötüleştiren önemli bir etken olduğu savlanmaktadır. Yardım etkinlikleri, bir yandan yoksunlukla mücadelede olumlu bir değer işlevi görürken bir yandan da engellilere yönelik sosyal baskının ve denetimin aracı haline geldiği için, doğası gereği tartışmalı ve çok boyutlu karmaşık ilişkiler içermektedir.

Yardım-hayırseverlik ekseninde şekillenen engellilik anlayışının yansımaları ve sosyal dışlanma ilişkisi engelli bireylerin deneyimleri ve düşüncelerinin yanı sıra devlet ve sivil toplum kuruluşlarının ilişkisi üzerinden de ele alınmaktadır. Engellilik ve sosyal dışlanmada yardım etkinliklerinin, rolünü kavrayabilmek için, bu çalışma kapsamında nitel çalışma metotları kullanılmıştır. Yaş ve toplumsal cinsiyetin farklı sosyal dışlanma ve engellilik deneyimleri ortaya çıkaracağı savlandığından, 18-40 ve 40+ yaş gruplarında eşit dağılım sağlanmış 8 kadın ve 8 erkek ortopedik engelli bireyle ve engellilik alanında çalışan 7 STK'nın temsilcileriyle derinlemesine mülakatlar gerçekleştirilmesini de içeren nitel bir araştırma yapılmıştır.

Derinlemesine incelenen veriler araştırma soruları göz önünde bulundurularak belirli başlıklarda gruplanarak incelenmiştir. Ancak bu çalışma, doğası gereği heterojen olan engellilik deneyiminin tümünü yansıtmamakta ve yalnızca incelenen grubu temsil etmektedir.

Bu araştırmada, "engelliliğin gelişen bir kavram olduğu ve engellilik durumunun, sakatlığı olan kişilerin topluma diğer bireyler ile birlikte eşit koşullarda tam ve etkin katılımını engelleyen tutumlar ve çevre koşullarının etkileşiminden kaynaklandığını" (UN CRPD, 2006) kavramsallaştıran engellilik tanımı kabul edilmektedir. Engellilik anlam ve deneyimini, politik ekonomi, sosyal ve kültürel bağlamda diğer bireylerle etkileşim içinde oluşturmaktadır. Bu sebeple, gerek politik ekonominin gerekse sosyal dönüşümlerin ve kültürel anlayışların engelliliğin ve sosyal dışlayıcı süreçlerin nasıl deneyimlendiği üzerinde önemli etkileri ve yansımaları vardır.

Engelli bireylerin paylaştığı deneyimler, engelli olan ve olmayan bireylerin engellilik hakkında farklı anlayışlarının bulunduğunu göstermektedir. Örneğin, engelli olmayan bireyler, engelliliği bireyci tıbbi model çerçevesinden fiziksel bir kısıtlılık, yetersizlik veya bir hastalık (ör: sıkça ifade edilen geçmiş olsun dilekleri) gibi değerlendirirken, engelli bireyler ağırlıklı olarak önyargılar, ayrımcı davranışlar, sosyal, politik, tutumsal ve fiziksel engellere atıf yaparak sosyal model söylemini benimsemektedirler.

Bu çalışmada, engellilerin çok çeşitli sosyal dışlanma deneyimleri yaşadıkları belirlenmiştir. Sosyal hayata eşit katılımı engelleyen; spor sahalarında ayrıştırılmış engelli tribünleri, engellilikle eşleştirilen yetersizlik algısı, düşük toplumsal beklentiler sebebiyle eğitim hayatından dışlanma, bireyin donanımlarına uygun olmayan düşük nitelikli iş teklifleri, hak ettikleri ifade edilmesine karşın bir türlü verilmeyen terfiler, yetişkin olarak görülmemek ve davranılmamak, çocukça hareketlere maruz kalmak, katılımcıların paylaştığı çok yönlü deneyimlerin bir kısmı olarak belirtilebilir. Engelli bireyler, yukarıda belirtilen deneyimlerin engelliliğin sosyal ve kültürel anlayışları ile doğrudan ilintili olduğunu düşünmektedirler. Ayrıca, engellilikle eşleştirilen belli rollerin (ör: yetersiz, muhtaç, işe yaramaz vs.) “yapabilirlikten yoksunluk” (Sen, 2000) yarattığı gözlemlenmiştir.

Engelliliğin hayırseverlik perspektifinden ele alınması ve engellilere yönelik yardım faaliyetlerinin yaygınlığı, toplumun engelliliği nasıl algıladığı ile yakından ilgilidir. Katılımcılara göre, toplum engelliliği yeti yitimi ile eş tutarak, engelli bireyleri, nasıl yaşamaları ve neye ihtiyaç duydukları gibi toplumsal anlayışın yansıması olan belli rollere hapsetmektedir. Yaş ve toplumsal cinsiyetten bağımsız olarak neredeyse tüm katılımcılar, engelli bireylerin toplum tarafından, aciz, işe yaramaz, gereksiz, saygın olmayan, acınası, eksik ve bağımlı bireyler olarak tanımlandığına dikkat çekmektedir.

Bu çalışma kapsamında engelli katılımcıların deneyimleri, toplumun konu engellilik olunca çok düşük bir beklenti düzeyine sahip olduğunu ve bu düşük beklentilerin engelli bireyler açısından kısıtlı yapabilirlikler olarak ciddi sonuçlar doğurduğunu ortaya koymaktadır. Düşük toplumsal beklentiler ve toplumun engelleyici rolüne cevaben, özellikle İngiltere ve Amerika Birleşik Devletlerinde siyasi olarak hareketlenen engelli hakları oluşumlarının aksine, Türkiye’de engelli bireyler kolektif hareketlilikten ziyade bireysel olarak insanüstü performans göstererek olumsuz toplumsal algılardan daha iyi olduklarını kanıtlama çabalarına yoğunlaşmaktadır. Engelli bireyler, beklenilenin üzerinde bir performans gösterdiklerinde ise toplum tarafından engellilere yönelik önyargıların değiştirilmediğine, bunun yerine başarı gösteren engelli bireylerin kişisel olarak kahramanlaştırıldığına ve diğer engellilere ilişkin mevcut önyargıların devam ettiğine dikkat çekmektedirler. Bu yaklaşım pek çok engelli tarafından toplumsal ikiyüzlülük olarak nitelendirilmektedir.

Engelli bireyleri belli rollerle sınırlayan ve düşük toplumsal beklentiler nedeniyle yapabilirliklerin kısıtlanması, katılımcıların çoğu tarafından ortak olarak deneyimlenirken, bazı dışlanma deneyimleri yaş ve toplumsal cinsiyete göre farklılık göstermektedir. Engelli kadınlar, çoğunlukla çocukça davranışlara maruz kalma, eğitimden dışlanma, farklılaşmış toplumsal cinsiyet rollerine atıfta bulunurken, engeli erkekler daha çok bağımlılık yaratan durumlar, sosyal yaşama katılımın önündeki engeller ve engelli olmanın her şeyin önüne geçen rolünün altını çizmektedirler.

Engelli kadınların eğitim yaşamında yaşadıkları sosyal dışlanma deneyimleri, 2002 Özürlüler Araştırması verileri ile de uyumludur. Zira engelli olmanın yanı sıra toplumsal cinsiyet de eğitim olanaklarına erişimde olumsuzluk yaratmaktadır. Bu durum, kadınları, eğitim başarısını gerekli kılmayan geleneksel toplumsal cinsiyet rolleri ile kısıtlayan anlayışın bir yansıması olarak da yorumlanabilir. Geleneksel olarak kadınları anne, eş, bakıcı rolleri ile sınırlayan ve bu rolleri ne derece yerine getirebildiği veya getirebileceği ile değerlendiren bakış açısı kadınlar için eğitime erişimi hayati önemde görmemektedir. Dolayısıyla engelli kadınların bu araştırma kapsamında paylaştıkları eğitim hayatından dışlanma deneyimlerinin yukarıda açıklanan eğilim ile ilişkili olduğu düşünülmektedir. Bunun ötesinde, engelli kadınların yalnızca eğitim hayatından dışlanmadığı aynı zamanda eş ve anne rolleri ile ilişkilendirilen yeterliliklerinin sorgulanması sebebiyle de duygusal anlamda sosyal dışlanmaya maruz kaldıkları gözlemlenmiştir.

Yaşlı engelliler ise oldukça dezavantajlı bir grubu oluşturmaktadır. Sıkça belirttikleri yalnızlık, azalan hareketlilik ve sosyalleşme imkanları, destek mekanizmalarına kısıtlı erişim imkanları, hem maddi hem de manevi ihtiyaçlarını karşılayamama endişelerinin, yaşla birlikte arttığını göstermektedir. STK'ların yardım faaliyetleri kapsamında, özellikle eğitim çağındaki genç engellileri öncelikli kılan seçim kriterleri, yaşlı engellilerin dışlayıcı süreçler karşısında daha korumasız kaldıkları ve dile getirdikleri endişelerinin haklılığını da ortaya koyar niteliktedir. Yaşlı engellilerin deneyimleri ve artan sosyal dışlanma riskleri, özellikle engellilik sebebiyle ortaya çıkan ekstra harcamalar sebebiyle de, engellilere yönelik kamu harcamalarının ve bu harcamaları düzenleyen hukuki çerçevenin engelli bireyler için ne kadar önem arz ettiğini göstermektedir.

Bu noktada, devletin engellilere yönelik sosyal politika araçlarına ve engellilik politikasına değinmek, engellilik, sosyal dışlanma ve yardım odaklı bakış açısı arasındaki karmaşık ilişkileri daha bütüncül değerlendirebilmek açısından gereklidir. Gerek engelli bireylerin deneyimleri gerekse 2022 sayılı yasa kapsamında engellilere sağlanan aylık düzenli gelir destekleri, evde bakım maaşı gibi kamusal sosyal desteklere ilişkin sağlanması beklenen gerekler (ör: gelir testinde hane halkı yaklaşımı), Türkiye'de engelliliğe yönelik sosyal politika araçlarının asgarici bir yaklaşımla muhtaçlık ekseninde şekillendiğini göstermektedir. Evrenselci yaklaşımdan uzak bir anlayışıyla, kamu bütçesi üzerindeki yükü azaltmak önceliğinde yapılan düzenlemeler, engellilerin söz konusu kamusal sosyal destekleri, diğer gelir getirici aktiviteler ile birlikte elde etmesine olanak sağlamamaktadır. Oysaki neredeyse tüm katılımcıların belirttiği üzere engellilik sebebiyle ortaya çıkan ekstra harcamalar, kamusal sosyal desteklerin önemini ve engellilerin bu desteklere olan ihtiyacının altını çizmektedir. Bu noktada, engelli bireyler, yurttaşlık temeline dayanan evrenselci bir yaklaşım benimseyen bir engellilik politikasının olmaması ve devletin engelli vatandaşlarının ihtiyaçlarına cevap vermekten uzak sosyal politika araçlarının "sadaka devleti" mantığının bir yansıması olduğunu ifade etmektedirler.

Engelli bireylerin ihtiyaç duyduğu yardımcı araç ve gereçler ile tedavi masraflarına ilişkin hasta katılım paylarını düzenleyen Sağlık Uygulama Tebliği (SUT), devlet nezdinde engellilere yönelik ayrımcı düzenlemeleri ortaya koymak açısından ve nasıl engelli olunduğuna bağlı olarak bir engelli vatandaşını diğer engelli vatandaşından ayrıcalıklı konumumda değerlendiren yasal düzenlemeler açısından önemli bilgiler sağlamaktadır. Özellikle yardımcı araç ve gereç ihtiyacının en yoğun olduğu engel gruplarından biri olan ortopedik engel grubunda, terörle mücadele kapsamında vazife malullüğü aylığı alanların veya 2011 yılında olan depremler sonucunda yaralanan veya engelli olanların söz konusu yardımcı gereçlere erişiminde katkı payı alınmazken, devlet diğer bir engelli vatandaşından katkı payı almaktadır. Engelli vatandaşlarının ihtiyaçlarına cevap vermede zaten yetersiz kalan sosyal politikalar, vatandaşlarına engelli olma durumları üzerinden de ayrımcılık uygulayarak hak ihlallerine yol açmaktadır. Söz konusu tebliğin esnek olmayan, sadece tıbbi eksende şekillenen tek tipçi yaklaşımı da yine engellileri ihtiyaçlarını karşılama konusunda çaresiz bırakmaktadır. Bu noktada, engelli katılımcılardan birinin ifadesiyle sosyal güvenlik kapsamında olmayanların, yardım kampanyaları aracılığıyla devletin sağladığı desteklerden daha fazla kaynağa, olanağa ve desteğe erişebildiği tespitinin önem arz ettiği düşünülmektedir. Yukarıda bahsi geçen kamusal sosyal desteklere ilişkin evrensel anlayıştan uzak uygulama ve hukuki çerçeve, engelli bireylerin ihtiyaçlarını karşılamada aile ve yardım kampanyaları gibi diğer destek mekanizmalarının önemini arttırmaktadır.

Ortopedik engelli bireylerin toplumun diğer kesimlerine göre engellilik sebebiyle daha yüksek harcamalara maruz kaldıklarını ortaya koyan deneyimleri, gerek kamusal sosyal desteklerin gerekse ihtiyaç duydukları yardımcı araç ve gereçlerin temini kapsamında sağlanan desteklerin önemini ortaya koymaktadır. Ancak hukuki çerçevedeki ayrımcı düzenlemeler ve muhtaçlık ekseninde şekillenen kamusal sosyal destekler, engellilerin bağımsız ve insanca yaşam sürmelerinin önünde engel teşkil etmektedir. Bu sebeple, engellilere yönelik sosyal politika araçlarının evrenselci yaklaşıma göre gözden geçirilmesi ve sağlanan desteklerin engellilerin ihtiyaçlarına cevap verebilecek düzeyde güncellenmesi gerekmektedir. Söz konusu düzenlemeler yapılırken Aile ve Sosyal Politikalar Bakanlığının alan deneyimi ve bilgisi olan hak temelli engelli STK'ları ile birlikte çalışmalar yürütmesi de kapsamlı değerlendirmeler açısından önemlidir.

Sosyal politika mekanizmaları oluşturmak veya mevcutları gözden geçirip değerlendirmek, sosyal politikaların hedeflediği kitlelerin kapsamlı analiz edilmesini gerektirir. Dolayısıyla, hedeflenen kitlenin sosyodemografik, sosyoekonomik özellikleri, beklentileri, problemleri, bölgesel farklılıkları vb. bilgileri içeren istatistiki veri çalışmaları ve bu verilerin analizine dayanan hedef kitle odaklı politika üretim süreçleri hayati önem arz etmektedir. Türkiye'de engellilerle ilgili en kapsamlı ve yeni istatistiki bilgi çalışması 2002 yılında gerçekleştirilmiştir. Yaklaşık 15 yıl önce yapılan çalışma, bu alandaki veri ve bilgi eksikliğinin en önemli göstergelerinden biridir. Hatta bu eski ve yetersiz istatistiki bilgi, Türkiye'de engellilik konusunun devlet düzeyinde ne kadar düşük öneme haiz bir konu olduğunun da bir yansıması olarak yorumlanabilmektedir. Türkiye'de engellik konusunda daha bütüncül ve tutarlı bir anlayış elde edebilmek adına mevcut durumun iyi analiz edilebilmesi için TÜİK, ASPB (Aile ve Sosyal Politikalara

Bakanlığı) ve engellilik alanında çalışan üniversitelerin işbirliğinde kapsamlı istatistiki çalışmalar yürütülmelidir.

2002 Özürlüler Araştırması da ortaya koymaktadır ki; Türkiye'de engellilik tanımlaması problemlidir. 2014 yılında Engelliler Hakkında Kanunda yapılan değişikliğe kadar engellilik, tıbbi bireyci model ekseninde tanımlanmakta ve yeti yitimi gruplarına ve normalliğe atıf yapan referanslar içermektedir. Her ne kadar 2014 yasa değişikliği ile sosyal modele güçlü atıflar yapılsa da, bu araştırma söz konusu değişikliklerin hala engelliliğin idari ve hukuki sınıflandırmasına yansımadığını ortaya koymaktadır. Hâlihazırda sosyal politika araçları, duruma göre kimin engelli olduğu kimin olmadığı tanımlarını bireyci tıbbi modelden almakta ve yalnızca sağlık uzmanlarının yoğun kontrol ve incelemesi ile belirlemektedir. Yasada sosyal model referansları ile değişiklik içeren ancak uygulamada tıbbi modelde kalan bu tutarsız yaklaşım devlet ve engelli vatandaşları arasında ciddi güven sorunlarına yol açmaktadır.

Bu çalışmada, STK temsilcileri ile yapılan görüşmeler, devlet STK ilişkilerine olduğu kadar, yardım-hayırseverlik ekseninde şekillenen engellilik anlayışına da ışık tutmaktadır. Görüşme gerçekleştirilen 7 STK'dan biri hariç tümüne, belediyeler, çeşitli kamu kurumları, politikacılar ve milletvekillerinden, ihtiyaç sahibi engelli bireylerin özellikle yardımcı araç ve gereç ihtiyaçlarının karşılanması kapsamında talep iletildiği belirlenmiştir. Evrenselci yaklaşımdan uzak ve engelli vatandaşlarının ihtiyaçlarını karşılamada yetersiz kalan sosyal politikalar sebebiyle politik olarak güçlü ve söz sahibi kesimlere ulaşmayı başarmış engelli bireyler, ihtiyaçlarını ve taleplerini elde ettikleri bireyci klientalist yardım kapsamında karşılarken bu iletişim ağına erişememiş engelliler için benzer olanakları sağlamak mümkün olmamaktadır. Sınırlı sayıda bireyin erişebildiği bu bireyci yardım odaklı enformel uygulamalar, kamu bütçesi üzerindeki yükü artırmadan siyasi açıdan da daha çok getiri sağlayan klientalist sonuçlar doğurmaktadır.

Türkiye'de engellilik alanında çalışan STK'ların, engelliliğin yardım odaklı değerlendirilmesinde önemli rolü bulunmaktadır. Gerek STK'lar ve devlet arasındaki güçlü hamilik ilişkileri (ör: kamu yararına dernek ve izinsiz yardım toplama yetkisine sahip kuruluş statüsünün devletçe belirlenmesi) gerekse STK'ların kurumsal olarak hayatta kalma ve engelli bireylerle olan ilişkilerini yardım ekseninde şekillendirmesi sebebiyle STK'ların temel faaliyetleri yardım kampanyalarına odaklanmaktadır. Hem engellilerle hem de STK temsilcileri ile yapılan görüşmeler, STKlar ve engelliler arasındaki ilişkilerin ihtiyaç ve ihtiyaçların karşılanması ekseninde yürüdüğünü ortaya koymaktadır. Bu yardım odaklı yaklaşım, STK'ların hak temelli ve engelli bireylerin çok yönlü sorunlarına odaklanmaktan uzak anlayışı ile birlikte, engelli bireylerin STK'lardan uzak durmasına yol açmakta ve engelli hakları hareketinin gelişiminin önünde önemli bir engel teşkil etmektedir. STK'ların bu yardım odaklı yaklaşımı devletin yerine getirmediği sorumluluklarını meşrulaştırmaya yol açmakta ve engellilere yönelik ayrımcı uygulamaları gündemde tutmak yerine, engelliliğin bireyci tıbbi model ekseninde değerlendirilmesine neden olmaktadır.

Engelliliğin hayırsever anlayışla yardım odaklı değerlendirilmesi ve yardım faaliyetlerinin yaygınlığı, köklerini yukarıda ortaya konan karmaşık ve iç içe geçmiş ilişkiler ve dışlayıcı süreçlerde bulmaktadır. Aynı zamanda Shakespeare'in (2000) de söylemiyle yardım; eşit olmayan, engelleyici bir toplumda bir gereklilik halini almaktadır.

Engellilerin yaşadığı sosyokültürel dışlanma deneyimlerinde, engellilerin medyada ve müfredatta yer alan temsili de etkili olmaktadır. Bu sebeple engellilik hakkındaki sosyal ve kültürel anlayışlar kapsamında ASPB ve hak temelli çalışan derneklerin işbirliğinde insan hakları temelinde şekillenen farkındalık çalışmaları büyük önem arz etmektedir. Ayrıca engellilerin gerek ulusal mevzuat düzeyinde gerekse uluslararası antlaşmalardan doğan hakları konusunda son derece düşük bilgiye sahip oldukları gözlemlenmiştir. Bu sebeple engellilere yönelik ulusal ve uluslararası mevzuata ilişkin erişilebilir bilgilendirme kanallarının Aile ve Sosyal Politikalar Bakanlığı öncülüğünde oluşturulmasının gerekli olduğu düşünülmektedir.

STK’ların yardım kampanyaları kapsamında kullandığı dil, görseller, söylemler, ve engellilerin temsili incelendiğinde, yardım etkinlikleri kişileri engelli olan ve olmayan biçiminde iki dışlayıcı gruba ayırmak yoluyla düalizm yaratmakta ve engelli bireylerin yaşadığı sosyokültürel dışlanmaya etki etmektedir. Toplumda yaygın olan engelliler muhtaçtır algısını pekiştirmekte ve yarattığı acıma duyguları ile engellilere yönelik sosyal baskıyı pekiştiren ilişkileri güçlendirmektedir. Engelli olmayan bireylere verdiği, “bize bağış yapın ki engellilere yardım edebilelim” mesajı ile engelliler yardım nesneleri haline dönüştürülmektedir. Ek olarak, yardım kampanyalarında sıklıkla kullanılan tekerlekli sandalyedeki engelli imajı, bazı engel gruplarının ihtiyaç ve beklentilerinin tüm engellilik deneyimine mal edilmesi sonucuna yol açmaktadır. Engelli bireylerin sorunlarına karşılık yardım etkinliklerini çözüm olarak öne çıkarmanın, sosyal dışlanma süreçlerinin kökenini gizlediği ve engellileri STK’lardan uzaklaştırarak engellilik aktivizminin gelişmesinin de önünü kestiği gözlemlenmiştir. Türkiye’de engellilere yönelik yardım kampanyaları, özellikle Hevey’nin (1992) yardım kampanyalarını incelediği üç aşamalı çalışmasının, birinci aşama söylem ve görsellerini benimseyerek, engelli bireyleri belirli rollere hapsetmekte (ör: bağımlı, muhtaç, umutsuz) ve engelliliğin sosyokültürel inşaasında önemli bir rol oynamaktadır.

Gerek engelliliğin sosyal ve kültürel olarak yetersizlik ve muhtaçlıkla eş değer tutulmasına yarattığı etki gerekse bireyci tıbbi modelden aldığı kökleri itibariyle yardım kampanyaları, Türkiye’deki engellilik sosyal dışlanma deneyimlerini derinden etkilemektedir. Aynı zamanda, sağlamcı zihniyeti pekiştirerek engelliliğin kültürel temsilinde de bir nevi yazarlık rolü üstlenmektedir. Bu sebeple, yardım kampanyalarının, devlet tarafından daha sıkı ve bütüncül değerlendirilmesi, birçok engelli tarafından ifade edilen yardım kampanyalarının ticari boyutunun da sıkı kontrol ve denetimlere tabii olması gerekliliğini doğurmaktadır.

Bu araştırma kapsamında sadece STK’ların değil devletin de engelliliği muhtaçlık ekseninde hayırsever anlayışıyla değerlendirdiği ve bu yaklaşımların engellilere yönelik sosyal baskının bireyselleştirilmesinde ve engellilik kapsamında yardım odaklı yaklaşımın baskın olmasında etkili olduğu gözlemlenmiştir. Engelli bireyler ve STK temsilcileri ile yapılan görüşmeler; engellilere yönelik yardım etkinlikleri, muhtaçlık ekseninde şekillenen sosyal politikalar, engellilik ve sosyokültürel dışlanma arasındaki ilişkinin; sosyal baskının bireyselleştirilmesi, ayrımcı uygulamaları besleyen yasama çalışmaları, engelliliğin tıbbileştirilmesi, STK'ların rolü ve öncelikleri, engelliliğin kültürel temsili ve dinsel etmenler gibi birbiriyle etkileşen karmaşık yapısal ve kültürel faktörleri içerdiğini belirlemiştir.

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