THE DEVELOPMENT OF DISABILITY PRIDE THROUGH CHALLENGING INTERNALIZED IDEALIST AND ABLEIST NORMS IN TURKISH SOCIETY: A GROUNDED THEORY STUDY

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ABSTRACT

THE DEVELOPMENT OF DISABILITY PRIDE THROUGH CHALLENGING INTERNALIZED IDEALIST AND ABLEIST NORMS IN TURKISH SOCIETY: A GROUNDED THEORY STUDY

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The aim of this study was to generate a theory on the self-concept development of Turkish people with physical disabilities in relation to their body appearance and functionality. The data was collected through semi-structural interviews conducted with 10 individuals with different types of physical disabilities requiring constant use of wheelchair. For the analysis of the qualitative data, grounded theory methodology was used. The results of the analysis revealed that the interaction between the presence of impairments and physical and attitudinal barriers in the society may lead to the internalization of idealist and ableist norms in the society, increasing the likelihood of longing for normality among disabled people. This path is associated with the feelings of shame regarding one's own body appearance and functionality. However, questioning and challenging these norms and their own internalizations enable disabled people to separate themselves from the society, giving them the chance to see their disability as a part of various ways of being, rather than a deficiency. As a result, disability pride becomes possible. The findings of this study mainly emphasized the importance of social arrangements ensuring independent living of disabled people for the personal growth, although the right to live independently is not implemented successfully in Turkey yet. This study was one of the few studies that bring the fields of clinical psychology and disability studies together, having practical and clinical implications to ameliorate the living conditions and psychological well-being of disabled people.

Keywords: People with physical disabilities, internalized ableism, independent living, disability pride, grounded theory

ÖZ

TÜRK TOPLUMUNDAKİ İDEALİST VE SAĞLAMCI NORMLARIN İÇSELLEŞTİRİLMESİNİN SORGULANMASI YOLUYLA ENGELLİLİK GURURUNUN GELİŞİMİ: BİR TEMELLENDİRİLMİŞ KURAM ÇALIŞMASI

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Bu çalışma, Türk fiziksel engelli bireylerin beden görünümü ve işlevselliğiyle ilişkili olarak benlik gelişimlerine dair bir kuram geliştirmek amacıyla yürütülmüştür. Çalışma verisi, sürekli tekerlekli sandalye kullanımını gerektirecek farklı tipte fiziksel engeli olan 10 farklı bireyle gerçekleştirilen yarı yapılandırılmış görüşmeler yoluyla toplanmıştır. Elde edilen nitel verinin analizinde, temellendirilmiş kuram metodolojisi kullanılmıştır. Analiz sonuçları, sakatlık ile toplumdaki fiziksel ve tutumsal engellerin varlığı arasındaki etkileşimin, toplumdaki idealist ve sağlamcı normların içselleşmesine yol açabildiğini ve engelli bireylerin normalliği arzulama ihtimalini arttırdığını göstermiştir. Bu yol, kişinin görünümüne ve işlevselliğine dair utanç duygularıyla ilişkilidir. Öte yandan, bu normların sorgulanması ve bunlara karşı çıkılması engelli bireylerin kendilerini toplumdan ayırmalarını sağlamakta ve onlara, engellerini bir eksiklikten ziyade, farklı varoluş biçimlerinden biri olarak görme şansını vermektedir. Engellilik gururu bu sayede mümkün olmaktadır. Türkiye'de bağımsız yaşam hakkının henüz başarıyla uygulanamamasına rağmen, bu çalışmanın sonuçları, temel olarak, engellilerin kişisel gelişimleri için, bağımsız yaşamı mümkün kılan toplumsal düzenlemelerin önemini vurgulamaktadır. Bu çalışma, klinik psikoloji ve engellilik çalışmaları alanlarını bir araya getiren az sayıdaki çalışmalardan biri olarak, engellilerin yaşam koşullarının ve psikolojik iyilik hallerinin geliştirilmesi pratik ve klinik öneme sahiptir.

Anahtar kelimeler: Fiziksel engelli bireyler, içselleştirilmiş sağlamcılık, bağımsız yaşam, engellilik gururu, temellendirilmiş kuram

To those who believe that
another world is possible

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> “*...a life in which not getting it is the point and not the problem; in which the project is to learn how not to ride the bicycle, how not to understand the poem*”
>
> — Adam Phillips

When I first read this, I thought to myself: “I’ll see you and raise you, Adam, I believe that the project is to learn how not to walk!”. In fact, this thesis, in which I explain in detail some of the ways to learn not to walk, is one of the results of me coining this thought of mine as my motto in life. However, this thesis wouldn’t be possible without the support of my thesis supervisor, my thesis monitoring committee, and the contributions of the participants.

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Approaching to the end of my Ph.D. education, I am not the same person I was at the beginning of this journey. As the saying goes, throughout these years, I got older and wiser. However, this significant change wouldn’t be possible without the support of the dearest people in my life.

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CHAPTER 1

INTRODUCTION

It wasn’t until I had a full-time job as a clinical psychologist in a university health clinic that I could start thinking about the meaning of being a disabled person. Previously, I had been busy with doing everything that others at my age were doing, such as going to school, having good grades, making friends, going out with them, exploring romantic relationships and sexuality, and so on. On one hand, I knew I was good at most of them, which had made me feel like I was just a person; on the other hand, I thought I would never be as good as others at some of them, which had made me feel like I was just my disability. Having a full-time job triggered the same feelings at the beginning: that I was on the right track but I was not adult enough as others seemed to me. Moreover, becoming adult was harder than any other goals I could reach until that time and I was hopeless about feeling as an integral part of the society with the difference in appearance and functionality of my body that wasn’t accepted either in my inner or outer world. With all of these thoughts and feelings complicating everything in my early adulthood, I started to think about the meaning of having a body with physical impairments in our modern world, which was structurally and socially designed for the majority, in order to find a balance between two poles I had been swinging, namely “normality” and “defectiveness”. Long after this, I have arrived to a point where I can understand that these are unrealistically extreme ends and I am neither at one end nor at the other. Also, I have acknowledged that disability is a concept closely associated with both psychological and social factors and I have started to evaluate the interaction between them. Actually, the current study is the result of my personal journey towards accepting myself as a disabled person faced with a variety of barriers in the society. Also, it is shaped by my interest to the fields of disability, appearance, and identity, all of which have had substantial effect on my continuing identity formation. Therefore, the following literature review will consist of the traditional and modern conceptualizations of disability, the role of corporeality within these conceptualizations, the contribution of appearance research on disability field, and the consequences of these psychological and social factors on the personal experiences of disabled people.

1. Disability

1.1.A Short Note on Terminology

The terminology referring disabled people has been changed during the course of history with the changes in the understanding of the concept of disability (Adams, Reiss & Serlin, 2015a). In this section, the conceptual definitions of impairment and disability will be briefly provided in order to clarify the terminology that will be used throughout this study. Although it has been frequently used interchangeable with the term “disability”, “impairment” refers to a physical or biological condition that is likely to cause a functional limitation. As a matter of fact, for some researchers impairment carries a meaning of deficiency, attributing the problem to the individual rather than the disabling system. Therefore, they argue that this word should be omitted from the field of disability studies. On the contrary, others maintain the idea that impairment describes the personal experience of disability, which differs from social or environmental aspects, and therefore, it should be preserved (Ralph, 2015). This is the reason for the preference of using this word throughout this study. On the other hand, as for the concept of “disability”, it is worth noting that it is harder to reach an agreement on its definition because it covers a great variety of social, political, and personal experiences. In other words, basically, disability refers to the interaction between people with impairments and social and environmental barriers that prevents their inclusion in the society (Adams et al., 2015a). Therefore, whereas impairment points out a physical fact, disability is constructed socially. In addition, this definition enabled the use of this word as a category of identity pointing out the marginalization of people with impairments by non-disabled people. In line with this explanation, identity-first language (e.g. a disabled person) was preferred over people-first language (e.g. a person with disability) in order to emphasize the role of the disabling structures within the society on the lives of people with impairments.

1.2.Historical Background

For decades, disabled people around the globe have been fighting shoulder to shoulder for their rights to live independently, to be free from discrimination and violence, to be fully included in the society, to have equal opportunities of education, employment, health and access to other social services, to have freedom of movement and nationality, and to participate in political and social life – and this fight have been and will be carried on from the perspective of right-based approaches to disability. Recently, these approaches have gained more significance among the academics and practitioners; however, from the beginning of the civilization, people with impairments have been evaluated from the perspective of normative standards within the society and disability has been extensively seen as a personal tragedy or a medical condition for a long time (Barnes, 2012). In fact, these viewpoints are still common and there is still a long way to go in order to ensure the full participation of disabled people to many modern societies.

Although people with impairments were integrated into the society as workers and citizens during ancient and medieval times, oppression, and prejudice against them were still prevalent. The impairments could be seen as a sign of demons or divine punishment and people with impairments could be killed. At the same time, they were seen as the passive recipients of compassion and support from the rest of the society. Following the rise of scientific methods and industrial revolution during the movements of Renaissance and Reform in Europe, marginalization of people with impairments has increased because impairments have begun to be perceived as deviances from the normality preventing individuals to contribute to the industrialized economic system which requires high standards of physical strength and intellectual capacity (Braddock & Parish, 2001). The perception of impairments as deviances from the normality led to the extreme discriminatory practices towards people with impairments such as segregation from the society through residential institutions or mass killings in Germany by the Nazi Government before the World War II. After that period, the number of people with impairments increased due to the injuries caused by the wars and due to the medical developments which prolonged people's lives but resulted in disabilities related to aging (Barnes, 2012).

The changes in the population characteristics in the second-half of 20th century contributed to the emergence of community-based services provided by the state with the traditional perspective to care in which disabled people has no control over the support they are provided. Therefore, disabled activists in Europe, Australia, and the United States of America started to reject the traditional approaches to disability and to request the redefinition of disability and related policies based on their own experiences. For instance, by the 1970's, two organizations, Disablement Income Group (DIG) and Union of the Physically Impaired against Segregation (UPIAS), which were set up and led by disabled people in the United Kingdom, challenged societies' views of disability and criticized the lack of economic opportunities for disabled people and their families to live independently and be included in the society (Oliver, 1996). In fact, UPIAS was one of the strongest organizations working from social model perspective, suggesting that:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from society. Disabled people are therefore an oppressed group. It follows from this analysis that having low incomes, for example, is only one aspect of our oppression. It is a consequence of our isolation and segregation in every area of social life, such as education, work, mobility, housing etc. (1976).

This argument has played a central role on the disability rights activism and the social model has been widely used as a basis during the fight for the rights of disabled people in many countries (Shakespeare, 2014). As disabled people had more voice in the field, the challenges to the barriers against their full participation to the society became stronger. The Independent Living Movement (ILM), which was originated from Berkeley, California during 1970's with the leadership of Ed Roberts, is one of the most important results of the change in the understanding of disability (White, Simpson, Gonda, Ravesloot, & Coble, 2010). This movement aims to change states' patriarchal and controlling attitudes over the lives of disabled people, to remove segregating practices, and to build a support system providing equality of opportunities and freedom of choices for the inclusion of disabled people in the society. Following these principles, the first Center for Independent Living (CIL) was established in 1972 in Berkeley, California, and the number of CILs led by disabled people gradually increased in the United States of America and Canada, as well as in European countries such as the United Kingdom, Finland, Switzerland, and Germany, and in other Asian and African countries such as Japan and Zimbabwe within a short period of time, providing services of peer support, personal assistance, and legal aid (Hayashi & Okuhira, 2008; Brennan, Traustadottir, Rice, & Anderberg, 2016). In fact, personal assistance is one the main tools for disabled people to achieve independent living, as this system enables them to employ their own personal assistants with economic support from the states and gives them the opportunity to control how, when, and from whom they will have support.

Another important development in the history of disability rights movement was the adoption of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in December 2006. In fact, it is the first human rights treaty of 21st century. Currently, there are 175 countries that have already ratified the convention, including Turkey. The main aim of the Convention is to ensure the full enjoyment of the basic human rights and fundamental freedoms of disabled people such as independent living, education, employment, political participation, freedom from discrimination, freedom from violence, and inclusion to the community. The Convention plays an important role as a source for the necessary implementations regarding the rights of disabled people as well as for the determination of their violations. In that sense, UNCRPD is an instrument with a social development dimension (UN, 2006)[1]. In the following section, a comparison between individual

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[1] Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html in December, 2017.

and social models of disability will be provided in order to clarify the positive influence of social model on the lives of disabled people.

1.3.Individual Model of Disability vs. Social Model of Disability

The history of disability, which was summarized above, includes plenty of examples for the interventions operated within a framework of personal tragedy and medicalization towards disability. The common ground of these interventions is the notion that impairments themselves are the causes of the segregation and exclusion of the people with impairments from the society. Therefore, through the lenses of tragedy model, disabled people don’t have the capacity to take control of their lives and are dependent upon the help from non-disabled people. This view reinforces charities which operate with non-disabled professionals and volunteers on behalf of disabled people. Moreover, disability is seen as something to be avoided or eradicated; and disabled people are seen as individuals who long for normality. For example, from this viewpoint, being dead is better than being disabled and this is the reasoning behind the policies and interventions such as the abortion of impaired fetuses, which remain unchallenged within the society. In fact, the tragedy model is constantly strengthened throughout the mainstream media representations, culture, and language and it becomes another source of disablement (Morris, 1991; Swain, & French, 2000). On the other hand, the medical model of disability argues that the person with impairments should be cured or medically treated so that they fit into the society rather than changing the society according to the needs of the person with impairments (Oliver, 2013). The literature under the influence of this framework extensively focuses on the medical explanations for impairments, personal troubles of having impairments and on the mechanisms of adaptation to disability with a functionalist perspective, without focusing on the social aspects of disability (Barnes, 2012), which results in the misrepresentation of the experiences of disabled people and correspondingly, the implementation of disabling policies and practices (Oliver, 1996).

Whereas the individual model tries to solve the problem of inclusion of disabled people by changing the individual through individualized services, such as wheelchairs, hearing aids, and pharmaceuticals, the social model locates disabling physical arrangements and attitudes at the heart of the problem. According to the social model of disability, disadvantaged status of disabled people is the result of the interaction between impairments and architectural, economical, political, cultural, and social factors. Therefore, disability becomes a social construction, as it is the case with other identities based on the gender, race, economic status, sexuality, and citizenship (Adams, Reiss, & Serlin, 2015b). In other words, physical or nonphysical barriers, such as the lack of accessibility, lack of different modes of communication (e.g. documents scanned or printed in Braille for blind people, and sign language users for deaf people), lack of education or employment opportunities, and lack of acceptance of diversity in appearance, are the reasons for the inability to be included to the society, rather than having physical, sensory, psycho-social or intellectual disabilities (Samaha, 2007). The introduction of social model into the field of disability followed by the publication of "Fundamental Principles of Disability" (1976) by UPIAS was described as "the big idea of disability movement" primarily because it provides a general cross-disability explanation to the problems faced by people with different types of impairments (Oliver, 2004). Moreover, usefulness of social model of disability as a tool to produce political and social change was proved when it triggered the adoption of human rights approach to disability and independent living philosophy (Campbell & Oliver, 1996). However, social model of disability has been criticized for not taking into account personal aspects of disability, which have unquestionable impacts on the lives of disabled people, although it was not proposed as an all-encompassing theory (Oliver, 2013). Thus, it seems important to review the current discussions in disability movement in order to have a wider perspective on this issue.

1.4.Beyond Individual and Social Models of Disability

The social model of disability defines the experience of disability as an interaction between individual and social factors (Oliver, 2013). In order to better understand this definition, researchers and activists in the field have taken an action towards explaining the effects of embodiment, ableism, and internalization of ableism on the everyday lives of disabled people. Moreover, although disability studies and clinical psychology are believed to have distinct understanding of disability, researchers begun to build bridges between those two disciplines (Simpson & Thomas, 2014).

1.4.1. Embodiment

Considering that "one's body is one's window on the world" (p. 335), disability is mainly experienced through impairments; however, following the rise of social model, mentioning biology, pain, or impairments has posed the risk to be evaluated from an individualized perspective, either as a tragedy or a medical diagnosis (Hughes & Paterson, 1997). Although it has been widely accepted that the social model has had progressive effects on disability movement, the main criticisms raised to social model gather around the argument that personal experiences of having a body with impairments in a world structurally and socially designed for non-disabled people are excluded from the disability field (Morris, 1991; Shakespeare, 2014), when impairments are categorized only in biological terms. Additionally, minimizing the body to its impairments and dysfunctions strips the meaning attached to the body through its individual and social history and defines it as a physical object separated from self (Hughes & Paterson, 1997). Consequently, debates on body and impairments have re-emerged within the disability theory, with the emphasis on the reflections of corporeality (i.e. "the state of living in/through/as a body"; Wilkerson, 2015) on the everyday lives of disabled people.

One side of the debates on embodiment in relation to disability is what Thomas (2010) calls "impairment effects", referring to "the direct and unavoidable impacts that 'impairments' (physical, sensory, intellectual, emotional) have on individuals' embodied functioning in the social world." (p. 37). The discussions on impairment effects, especially in the field of medical sociology, include disabled people's relationships with their own symptoms and bodies, with their own selves as a patient, and with the medical system including doctors and care workers. Moreover, Thomas (2012) argues that impairments are bio-socially and culturally constructed, since the biological and social factors of impairments cannot be separated from each other. This kind of conceptualization within disability studies is meaningful, because environments are disabling only for those who have actual impairments; and they are worsened by the environmental and social barriers. Therefore, there is not a clear line between impairments and disability within the everyday lives of disabled people, in contrast to what it is suggested by the strong social model of disability (Shakespeare, 2014).

Secondly, the sociological research and theory of the meaning of body, which revealed that body is a source to understand the inner lives of individuals, as well as a determining factor of "privilege, status, and power" in the society, underpinned the research on embodied experience of disability (Turner, 2001; Garland Thompson, 1997), suggesting that body carries a meaning more than the physicality. In fact, body is the site based on which discrimination and othering occur. Therefore, there is an intersectional relationship between disability, gender, sexuality, and race, all of which are the subject of body politics (Wilkerson, 2015). In addition, debates on embodiment within disability studies enabled the questioning of social norms about the acceptable bodies, giving voice to those whose experiences were denied, invalidated, or unnoticed because they do not conform what is accepted as "normal" (Lisi, 1994; Zitzelsberger, 2005). For instance, in a qualitative study conducted with people with visible physical impairments, it was concluded that invalidation of bodies with impairments resulted in threats to their existence in various areas of their everyday lives (e.g. economic, cultural, social, and emotional), although resistance to the oppression was possible (Loja, Costa, Hughes, & Menezes, 2013). Similarly, another qualitative study conducted to explore the effects of the impairments revealed that disability was associated with the loss of independence, employment, and/or attractiveness and desirability (Galvin, 2005). However, it was also observed that participants could find ways to develop positive identities by challenging and changing normative standards of independence and attractiveness. As it has been emphasized in a study conducted with an aim to discuss cultural consequences of impairments on women,

> [disabled people] are the only group of people who are trying to push that broadening of acceptance beyond culture and race, towards a broadening acceptance for everybody . . . that would free men and women from the stereotypes of how men and women need to be emotionally or physically (Lisi, 1994, p. 206).

In other words, researches and theories on embodiment in disability challenge the notion of perfection, which reinforces the as-old-as-history myth that bodily perfection can be and should be achieved (Stone, 1995). This myth is one of the sources of the understanding for disability as a diminished state of being, together with ableism and internalized ableism, which will be discussed in the following section.

1.4.2. Ableism and Internalized Ableism

As the literature on disability studies gradually grows, wider variety of social and psychological processes associated with the experience of disability is discussed. In that sense, ableism and internalized ableism are relatively new concepts in the field. Ableism is defined as “a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human” (Campbell, 2001, p. 44). In other words, the presence of ableist norms in the society imposes that having impairments diminishes the state of the individual as a member of that society and creates the notion of disability by producing the preferred category of ableness (Campbell, 2008). McRuer (2006) names this phenomenon as ‘compulsory able-bodiedness’ and suggests that stigmatization of people with impairments who fail to conform to the ableist norms in the society is reinforced by legislative and executive authorities (as cited in Harnish, 2017). For instance, the segregation of disabled people in institutions is justified through several ableist assumptions about people with impairments. First, disability is seen as an individual problem which should be under the surveillance of several professionals. Second, people with impairments are not believed to be capable of living independently and deciding for themselves; thus, it is for their own good to be cared by institutions. Third, they are so different than others that their segregation from the rest of the society is plausible (Carlson, 2015). As it can be seen from this example, disabling structures within the society are maintained through ableist assumptions.

In a world that is structurally and socially designed for non-disabled people, everyone, whether disabled or not, is exposed to ableist messages and practices related to the negativity of impairments and inferiority of disabled people, demonstrating the extent of the impact of politics of ableism (Campbell, 2008). In fact, Reeve (2012) defines psycho-emotional disablism as the inner barriers that result from the interaction of disabled people with others (i.e. direct psycho-emotional disablism) or with structural barriers (i.e. indirect psycho-emotional disablism). Thus, internalization of ableist norms in the society is a consequence of psycho-emotional disablism, happening when prejudices towards disability are internalized by the people with impairments themselves and which leads to the feelings of invalidation among them. According to Campbell (2008) internalized ableism is maintained through two strategies: "the distancing of disabled people from each other and the emulation by disabled people of ableist norms" (p. 155), both of which leads to limited opportunities to form a collective culture of disability and to challenge ableist societal norms. Besides, there have been several studies conducted to investigate the impact of having visible impairments on interpersonal relationships; and many accounts in these studies reflect participants' internalizations of exclusion in different contexts (such as work or romantic relationships and sexuality) because of their disabilities (Taleporos & McCabe, 2002; Sheldon, Renwick & Yoshida, 2011; Naidu, 2015), demonstrating their acceptance of exclusion from the society based on the otherness that is imposed on their bodies and selves. Therefore, in order to defend the rights of disabled people within the social model framework, understanding psycho-emotional aspects of disablism is crucially important (Watermeyer & Swartz, 2008). Only in this way is it possible to develop a disability theory based on the personal experience of disabled people.

1.4.3. Disability Studies and Clinical Psychology

As the history of disability movement demonstrates, “disability studies” is an interdisciplinary field, integrating many areas of study such as sociology, history, medical anthropology, and politics. However, until recently, psychology, especially clinical psychology, has been left out of this coalition because of its particular interest in individuals, which used to be seen as a risk for undermining the social model of disability (except of its use in rehabilitation field). In fact, for a long time, clinical psychology and psychiatry conceptualized impairments as the deviances from the norm which should be fixed. As a result, individual aspects of having impairments were overlooked and both disability studies and clinical psychology were criticized for not bridging the gap between them (Olkin & Pledger, 2003). However, recently, researchers have started to explore the ways how disability studies can benefit from clinical psychology in order to facilitate the social change through empowerment of disabled people and community (Goodley & Lawthorn, 2006; Meekosha & Shuttleworth, 2009).

The ignorance of psychological aspects of having disabilities does not have negative impact only on the disability politics but also on the psycho-emotional well-being of disabled people. Actually, denying disabled people’s personal feelings and struggles about their impairments is another kind of oppression, which in turn leads to the feelings of shame and rejection of the identity (Watermeyer & Swartz, 2008). However, researchers in disability studies have been very cautious about integrating psychology into the field of disability and have discussed the ways in which clinical psychology can be really helpful. For instance, Goodley (2012) suggests that adopting functionalist approach in psychology inherently contains the assumptions of lack, deficiency, or deviancy from the normality for people with physical, sensory, intellectual and emotional disabilities, carrying the possibility to personalize the experience of disability. On the other hand, phenomenological approaches in psychology take individual aspects of disability into consideration with an emphasis on the experience of living with impairments in disabling environments. In that sense, studies examining the meaning given by disabled people to the experience of disability and investigating its interaction with the society have valuable contributions to the field of disability (see Lisi, 1995; Galvin, 2005).

Although there have been changes within the field of clinical psychology, which has lately become more socially or culturally oriented in conceptualizing individual cases, it is predicted that this change will remain limited because of the nature of clinical applications in psychology. However, the contribution of the collaboration between these two fields is not beneficial only for disability studies but also for psychology because disability studies will provide a wider perspective about disablism, which seems to be crucial to conduct culturally sensitive psychotherapy with patients with impairments (Olkin, 1999; Simpson & Thomas, 2014). In fact, the vast majority of ableist messages in the society and the lack of any formal education on disability issues in undergraduate and graduate psychology programs, as well as in psychology textbooks, might be already resulting in biases in case conceptualization and intervention during psychotherapy with people with impairments (Olkin & Pledger, 2003). Thus, research in disability studies enables psychotherapists to offer better quality services to people with impairments, which is essential to support their mental health.

1.5.Disability Movement in Turkey

According to results of the Turkey Disability Survey (DIE, 2002), conducted in cooperation with the General Directorate of the Prime Ministry Administration for Disabled People, 12.29% of the population (approximately 8.5 million persons) has been living with at least one type of disability, such as chronic diseases, psychiatric conditions, mobility disabilities, visual disabilities, hearing disabilities, speech and language disabilities, and intellectual disabilities. Moreover, the results of this research has also revealed that disabled people in Turkey experience difficulties in participating to the society, including education, employment, participation to social life, and access to health care services (Tufan, Yaman, & Arun, 2007). Similarly, Survey on Problems and Expectations of Disabled People (2010), conducted by Turkish Statistical Institute, has further emphasized that disabled people face discrimination and exclusion from the society as a result of inaccessible environments, lack of assistance and support, lack of opportunities and social services, and social prejudices. Therefore, considering the problems that high number of disabled people has to face on a regular basis, it is important to understand the current condition of the basic human rights of disabled people and their right-based movement in Turkey. Until lately, legal perspective towards the rights of disabled people in Turkey was under the influence of medical model of disability. However, in 2014, important changes were made on the law that was accepted in 2005 regarding the rights of disabled people. With these changes, disabled people's rights of full and equal participation to the society and freedom from discrimination and exclusion are recognized and secured by the law (which is now called as "Law on People with Disabilities", Turkey, Law No. 5378, 2015). In addition, Turkey was one of the first countries that accepted and ratified the UNCRPD in 2007 (Law 5825, Turkey). However, the extent of the implementation of these laws and regulations is still a concern for disabled people and their right-based organizations, since the discrimination and exclusion are still prevalent in the lives of disabled people.

As it is the case with any other minority group movement in the world, the disability movement in Turkey has been influenced by the social, economic and political changes. The increase in discussions on identity politics especially after the military takeover in Turkey in 1980's enabled the awareness on the importance of civil society for the lives of disabled people, although it possibly had also a negative impact on the social movement of disability by preventing disabled people to form their right-based organizations during the political atmosphere of that time (Ertürk, 2003). Besides, it has been revealed that the majority of disability movement in Turkey is shaped by a "strong-state" tradition, which negatively influenced the strength of social policy because a system based on charities was institutionalized for their benefits to the state. Moreover, majority of disabled and non-disabled people make sense of the experience of disability from a religious perspective, which results in the “emphasis on understanding and compassion, rather than a legitimate political struggle for citizenship rights” (Bezmez & Yardımcı, 2010, p. 608). Lastly, the socio-economic status of disabled people whose significant proportion is illiterate and unemployed because of the barriers in the society is another challenge for the right-based struggle to be started. In fact, disabled people face difficulties to get organized to fight for their rights and therefore, they are compelled to a position where they rely on charities for their basic needs. Despite all these factors, Bezmez and Yardımcı (2010) have stated that there are newly emerging right-based discourses with the increased use of Internet and the influence of European Union policies in Turkey.

As for the Independent Living Movement, which is another right-based disability movement that have recently gained more strength mainly in Western societies since 1970’s as it was summarized before, studies on the implementation of the right to live independently of disabled people in Turkey have revealed that although there are some improvements in the living conditions of disabled people, there are many disabled people whose right to live independently is seriously violated. In fact, although Turkey accepted and ratified the UNCRPD in 2007, which states in the Article 19 that parties should make the arrangements that enable disabled people to ensure their right to live independently and to be included to the society, the “Roadmap for the Implementation of the Article 19 of UNCRPD in Turkey” that is prepared at the end of the project conducted by Human Rights in Mental Health Initiative (Ruh Sağlığında İnsan Hakları Girişimi – RUSİHAK) in cooperation with Center for Independent Living – Sofia and European Network on Independent Living (ENIL) in 2015 clearly illustrates that many disabled people in Turkey are forced to live in institutions where care is provided from a traditional perspective. Therefore, disabled people living in institutions have no control or freedom over the support they are provided for their needs, and have no opportunities to be included to the community[2].

In conclusion, social, economic, and political factors play an important role in the development of disability movement in Turkey. Although there are improvements regarding the understanding of disability from a social and right-based perspective, the need to spread this struggle from the ground to the top persists. This is the only way for disabled people to fully enjoy all their human rights and fundamental freedoms as it is stated in the CRPD (UN, 2006).

2. Appearance Research

“Body image” is a multifaceted concept pointing out to cognitive, emotional, behavioral components related to the psychological experience of the body (Cash, 2004). Beside these subjective components, body image includes relational and social aspects as well. The literature mostly focuses on cognitive distortions, irrational thoughts and beliefs (Butters & Cash, 1987; Wang, Houshyar, & Prinstein, 2006; Noles, Cash, & Winstead, 1985), self-conscious and other basic emotions (Crocker et al., 2014; Castonguay, Brunet, Ferguson, & Sabiston, 2012), and eating, dieting, and over-exercising behaviors (Robinson & Bacon, 1996; Allaz, Bernstein, Rouget, Archinard, & Morabia, 1998; Schuster, Nagy, & Tantleff-Dunn, 2013) associated with low body satisfaction. On the other hand, relational and social aspects of body image have been explained by several psychosocial theories such as social comparison theory (Festinger, 1954), which indicates that the body image is shaped by social comparisons with others encountered either in real-world or in the media (as cited in Eyal & Te'eni-Harari, 2013), and self-objectification theory (Fredrickson & Roberts, 1997), which emphasizes the importance of physical appearance for cultures perceiving the body as a social object to be evaluated. However, majority of the studies in the literature of body image have been conducted in relation to weight satisfaction and the need for further examination of

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[2] The project “Independent Living Network (ILNET): Promoting the right to independent living of people with disabilities in Turkey” was completed in 2015. The report was accessed in 2016 from the project website http://ilnet.enil.eu, which is down at the time of writing this thesis.

the specific effects of appearance altering conditions, such as congenital or acquired physical disabilities, remains stable (Cash, 2004).

2.1.Body Image and Disability

There has been separately growing research on the effects physical disabilities on body image. Lawrance (1991) underlines the importance of physical activities on the formation of the self-concept and he notes that congenital physical disabilities (e.g. cerebral palsy and spina bifida) might interrupt this process because they result in problems with receiving, interpreting, and responding to stimuli. However, most of the studies have been conducted with individuals who have acquired disabilities as a result of accidents, operations, and complex diseases. For instance, according to a qualitative study conducted with individuals having varying degrees of acquired physical disabilities, the internalized attitudes of the society towards physical differences were maintained by the subjective “feelings of inadequacy and unattractiveness” (Taleporos & McCabe, 2002). Moreover, the results revealed increased visibility of the disability was associated with increased subjective distress about the disabling condition. Similarly, Yuen and Hanson (2002) found out that women with spinal cord injury scored higher on appearance orientation, which was explained as the amount of time spent with the concerns on the physical appearance, although there has been a lack of consistent findings about this relationship.

Body image is not only affected by the visual differences in the body shape, but also by the function and potential of the body (Smith, 1984; as cited in Taleporos & McCabe, 2002). In fact, a review study examining the case reports conducted with both disabled and disordered eating individuals revealed that there are emotional, perceptional and social differences in terms of body experience between able-bodied and non-able-bodied individuals. For instance, especially individuals with mobility-related disabilities had worries about others’ judgments and reactions to their limited physical activities, hence their dependence to others. Moreover, social messages idealizing both thinness and independency from a variety of sources, such as families, peers, and medical staff had negative influences on body satisfaction. Studies including individuals with both disability and a form of eating disorder revealed lower dissatisfaction about the body weight than non-disabled but eating disordered individuals, indicating that internalization of thin ideal might not be a focal point for this population who deals with broader range of body-related problems, such as the feelings of being dependent and burdensome (Cicmil & Eli, 2014).

As is the case with non-disabled people, Dawn (2014) argues that portrayal of "perfect bodies" in the media triggers body-related problems among disabled people through the process of social comparison which results in the devaluation of people who cannot conform to that ideal. Moreover, disabled people are underrepresented in the media and the existing representations in television shows, cinema, and literature are usually based on the long-standing assumptions and prejudice against disabled people in the mainstream culture, contributing to the negative understanding of disability within the society (Dawn, 2014). As a result of these, bodies with impairments become object of stare and disturbing reactions from non-disabled others, having a negative effect on disabled people's perceptions of their bodies. The reactions that disabled people get from others, who can easily violate disabled people's privacy and/or invade their personal space just because they look different (Morris, 1991), range from stare to comments, including pity, curiosity, 'heroic', or positive views, and to be treated invisible. Some of these reactions have more harming effect on disabled people than others (Loja et al., 2013). With the internalized norms of perfection and normalcy, these reactions pose greater risk for disabled people of having negative feelings towards their own bodies such as invalidation and shame, although these feelings may change over time as they move towards identity transformation (Galvin, 2005).

2.2.Body-Related Shame and Disability

Lewis (1971) defines the emotion of shame based on the role of the self when it is triggered. In that sense, when people feel ashamed, they become the focus of negative evaluation and perceive their whole selves as defective and objectionable and therefore, make internal, stable, uncontrollable, and global attributions. Moreover, shame is associated with perceived loss of status in the community and feelings of failure to meet the standards. These experiences result in the need to hide and disappear (as cited in Tangney, Miller, Flicker, & Barlow, 1996; Tracy & Robins, 2004). The sources and the consequences of body shame have been extensively investigated within appearance research. For instance, lately, Bessenoff and Snow (2006) revealed that perceived cultural norms and personal ideals were related with body shame, although cultural standards became problematic only if they were taken as ideals, indicating the importance of the interaction between external and internal factors. Researchers claim that culturally accepted norms of beauty and independence might also lead to negative self-perceptions among disabled people because internalization of high standards is associated with devaluing attitudes towards the self. For instance, Rumsey (2002) indicates that congenital disfigurements such as cleft lip increase risks for problems in self-esteem, with the possibility of avoidance of social interactions as an indication of shame, although positive adaptation is possible. These results are consistent with other studies indicating that compared to non-disabled people, people with physical impairments are more concerned with their appearances and spend more time to use appearance strategies (such as hiding body parts that are evaluated negatively) in order to reach normalcy and positive evaluation (Dewis, 1989; Yuen & Hanson, 2002). These results demonstrate that the internalization of beauty standards is an important factor eliciting body-related shame among people with impairments.

Loss of independence as a result of physical disability is another source of shame among people with impairments, especially because of the idealization of independency in the Western societies. Galvin (2005) indicated that especially those who didn’t have access to independent living opportunities, such as paid assistants, expressed more feelings of shame in relation to their physical needs and dependency, as a result of the internalization of societal perception that having physical needs is being inadequate or inferior human being. Moreover, in the same study, acquiring a physical disability was associated with the experience of losing paid work, which also caused losing one’s social status, increasing feelings of shame related to the functionality of their bodies. In fact, in their review on eating disorders and disability, Cicmil & Eli (2014) revealed that negative comments regarding dependency might have more adverse effects on body image of disabled people when they were combined with negative comments on body weight or shape. In that sense, one of the most negatively affected aspects of disabled people’s lives by body-related problems is romantic relationships and sexuality.

2.3.Romantic Relationships, Sexuality and Disability

Until lately, romantic relationships and sexuality of disabled people has been investigated from a medical perspective, which formulizes it either as an absence or a problem, yet with lesser significance than other rehabilitation issues. Moreover, discussions on disability and sexuality have mostly lacked the voices of people with impairments until the social model is widely accepted, which encourages disabled people to speak for themselves and to fight against exclusion and discrimination (Shakespeare, Gillespie-Sells, & Davies, 1996, pp. 1-4). Since then, the literature on romantic relationships, sexuality and disability has been expanded gradually, especially in Western societies.

Researchers in the field of disability and sexuality have recently focused on the pleasurable aspects of sexuality of disabled people (Tepper, 2000; Loeser, Pini, & Crowley, 2017) and the barriers to disabled people’s engagement in healthy and fulfilling sex lives (Campbell, 2017). Although some researchers argue that physical impairments such as multiple sclerosis, spinal cord injuries, and brain damage might have a negative impact on sexuality because they interfere with the ability to engage in physical activities during sexual practices, others emphasize the role of culture and society in the understanding of sexuality of disabled people (Murphy, 2005). From the second perspective, because sexuality is determined by the context in which it is experienced, the main barriers to the sexuality of disabled people are myths and taboos that are present in the society regarding their sexuality (Mannino, Giunta, & La Fiura, 2017). In fact, Berman et al. (1999) reveals that social barriers have more adverse effects on sexual development of children and adolescents with disabilities compared to the effects of impairments on their sexuality. These barriers include the common beliefs that a) disabled people have no sexual needs or desires, b) sexuality belongs to non-disabled people because disabled people are not sexually attractive or cannot have sex, and c) they cannot have a healthy sexual life and therefore, they should be protected from sexual harassment and abuse (Sibanda, 2015). As a result, not only do disabled people experience difficulties in exploring and expressing their sexuality but they also face discrimination and exclusion in many areas of their lives. For instance, Berman et al. (1999) reports that a high proportion of children and adolescents with congenital physical disabilities have less access to sex education and those who has had some form of sex education did not find it useful because it did not address to their unique concerns about sexuality. Similarly, in a recent study, it was noted that the access to sex education of disabled adolescents differed according to the type and severity of disability, which indicated that adolescents with more severe intellectual disabilities were less likely to have sex education than their peers with other types or less severe disabilities (Barnard-Brak, Schmidt, Chesnut, Wei, & Richman, 2014). Therefore, it can be concluded that the lack of sex education undermines safe and healthy exploration of sexuality of disabled children and adolescents (Murphy, 2005).

Another problem area is the inaccessibility of sexual and reproductive health and rights services for disabled people. Actually, Nguyen, Liamputtong, and Monfries (2014), who used meta-synthesis approach to analyze 15 qualitative studies on sexuality and disability, found out that health service availability and accessibility was one of the main external factors that restrict disabled people’s access to sexual information and care. Besides, it was revealed that previous negative experiences with health care providers resulted in the difficulties to seek for professional support. Similarly, Manoj and Suja (2017) emphasized that the barriers to sexual and reproductive health services were associated with higher risk of being subjected to harassment and abuse, and sexually transmitted diseases. Therefore, besides developing more inclusive sex education for children and adolescents with impairments, it was suggested that sexual and reproductive health service providers should have more awareness on the intersectionality of disability and sexuality (Kattari, 2014; Nguyen et al., 2014).

Apart from the problems in accessing to social services of sexual and reproductive health and rights, the psychological effects of physical and social barriers to the sexuality of disabled people have been investigated extensively. Yet, because of the complexity of the topic, which includes biological, psychological, and social aspects, studies on disability and sexuality do not yield one-directional results in terms of their association with psychological well-being. In other words, how disabled people make sense of their impairments and disabilities varies from one person to another, which might result in negative, neutral, or positive appraisals regarding the impact of disability on sexual esteem, sexual satisfaction, and sexual behaviors. In that sense, Taleporos and McCabe (2001) state that disabled people face common barriers to express their sexuality, to have sexual satisfaction, to see themselves as a sexual being, and to engage in sexual behaviors due to their disabilities and societal attitudes towards them. Also, this effect is accentuated for people who have more severe impairments. These results are in congruence with the results of a recent study conducted with varying types of physical disabilities, reporting the level of sexual satisfaction increases as the level of self-reported independence also increases (Kattari & Turner, 2017). However, for some disabled people, their impairments do not have any negative influences on their sexual esteem. On the contrary, they believe that their disability has positively affected their sexual behaviors by helping them to approach sexuality in more creative and flexible ways. Moreover, this kind of appraisal is even more likely for disabled people who experience their disability for longer periods of time. In fact, this phenomenon can be explained by the possibility that people with impairments find ways to accept and overcome their physical limitations (e.g. learning new techniques), and to enjoy their sexuality with time (McCabe & Taleporos, 2003). In addition to that, Kattari (2014) emphasizes the positive role of the connection with the partners on the sexual esteem of disabled people, which includes support, adaptation to the creative solutions for their needs, and validation within the relationship.

Interestingly, sexual satisfaction and pleasure is rarely a discussion within the field of sexuality and disability. However, Tepper (2000) argues that pleasure, especially the one that is derived from sexuality, is very important for everyone in the sense that it helps people to feel alive and to cope with physical and emotional pain as well as it increases the sense of connectedness with the world and with others. Besides, sexual pleasure has a protective role against the mainstream messages that only “the ideal body” is worthy for pleasure. On the other hand, the lack of discussions of sexual pleasure among disabled people contributes to the maintenance of false beliefs regarding the sexuality of disabled people in the society (Tepper, 2000). For instance, Turner (2012) expresses one of the most common assumptions: disabled people do not have sex for pleasure (as cited in Kattari & Turner, 2017), which is also associated with the assertion that coitus is the main aim of sexuality. However, it is also shown that nonpenetrative sexual activities are important sources of sexual satisfaction among disabled people such as deep kissing, oral sex, or nude cuddling (McCabe & Taleporos, 2003) and masturbation (both solo and with partner), fondling, rubbing, fingering, using sex toys and so on (Kattari & Turner, 2017), indicating that the definition of sex and source of sexual pleasure differs from one person to another.

In this section, the impacts of impairments and disabilities on the sexual esteem of disabled people have been summarized. Following, the literature on the relationship between physical disabilities and self-concept will be discussed, with a deeper focus on disability identity and pride.

2.4.Self-Concept and Disability

Self-concept has been an important area of study within psychological research. Shavelson, Hubner, and Stanton (1976) define self-concept as the people’s perception of themselves, which is shaped by their interactions with their environment, and significant others. The relationship between self-concept and body image has been extensively studied with a variety of population such as children (Bennett, 1987; Guyot, Fairchild, & Hill, 1981; Story, 1979), adolescents (Berkowitz, Gehrman, Wadden, Sarwer, & Cronquist, 2004; Brantley & Clifford, 1976; Lerner & Karabenick, 1974), and individuals with various psychopathologies (Girodo & Boyer, 1992; Mori & Morey, 1991; Weckowicz & Sommer, 1960), all of which aims to understand the impact of corporeality on the people's perception of themselves. Therefore, within this research area, one of the most studied populations has been people with disabilities.

The literature on body image, self-concept, and disability yields inconsistent results about the self-concept of people with disabilities regarding to the appearance and functionality of their bodies, in which the relationship might be found to be positive, neutral, or negative, although a recent meta-analysis has revealed that self-concept of youth with disabilities is poorer than their non-disabled peers (Ferro & Boyle, 2013). However, it is worth to note that most of the research focuses on the self-esteem aspect of self-concept whereas disability self-concept includes aspects like disability self-efficacy and sense of disability identity (Bogart, 2014). In that sense, the disability self-concept indicates the extent that disabled people can manage their disability-related needs in a way that they can reach to the goals they set for themselves (Amtmann et al., 2012) and the extent that they can feel as a part of a larger group that have common experiences, which plays an important role to support their self-esteem (Dunn & Burcaw, 2013). In fact, according to Oyserman, Elmore, and Smith (2012), different parts of self-concept are combined at the concept of identity. Therefore, the disability identity and pride will be discussed more in detail below.

2.4.1. Disability Identity and Pride

The development of disability identity has been mostly investigated through qualitative studies with an individual focus. In fact, the literature on the development of disability identity is important because it is through their identities that disabled people can make sense of their impairment, their bodies, and their relationships with the outside world, whereas this interaction also shapes the development of disability identity (Forber-Pratt, Lyev, Mueller, & Samples, 2017).

From the disability rights perspective, the source of disability identity, similar to identities regarding race, gender, and sexual orientation, is the membership to the minority group of disabled people who share experiences of prejudice and discrimination (Dunn & Burcaw, 2013). Many researchers have suggested that disability identity can buffer against the difficulties of being subjected to oppression by the mainstream society and can help people with disabilities to adapt to their physical realities (Dunn & Burcaw, 2013; Olkin & Pledger, 2003). In fact, contrary to the society's widespread belief that disabled people want to change who they are, even if it means rejecting their identities, it is demonstrated that the experience of disability, whether it is congenital or acquired, allows to have an interesting perspective on life, that can be used positively (Swain & French, 2000). In line with this suggestion, it is stated that positive affirmation of the disability identity among disabled activists is associated with the rejection of "cure", further indicating that there is a positive relationship between adherence to social model of disability and activism (Hahn & Belt, 2004). Similarly, Nario-Redmond, Noel, and Fern (2013) have found out that if disabled people claim disability as the most important aspect of their identity, they are more likely to see their disabilities as something valuable, to express pride, and to fight against the disabling system. Therefore, as Galvin (2005) points out, it is possible to see the experience of disability not as a personal tragedy but as a consequence of social structures that can be challenged. In fact, this is how the oppressing attitudes of the society, regarding the idealization of normality and independence can become a question of debate among people with impairments (Galvin, 2005). However, it is worth to note that acquiring a disability identity is a personal issue, which is shaped by the personal life experiences and which shifts disabled people's perception of themselves from stigma-based identity to disability pride (Forber-Pratt et al., 2017).

Disability pride is acknowledged as a key element of a disability identity with its four components: a) claiming disability, b) believing that impairments and disabilities are common experiences, c) believing that cultural, social, and environmental factors have negative effects on the experience of impairments, and d) feeling as a part of a cultural minority group as a result of having impairment (Putnam, 2005). Actually, the shift in the perception of disability has helped disabled people to reject the ideas that disabilities indicate individual failings, and disabled people are inferior to non-disabled people (Darling & Heckert, 2010). In line with this claim, Nario-Redmond et al. (2013) have demonstrated that in an individual level, seeing disability as a source of pride is a predictor for more positive sense of self. However, Hahn and Belt (2004) have emphasized that disabled people’s positive perceptions about themselves do not have much support from ableist societies, compelling them to fight against strong social norms. Therefore, acquiring disability pride might take time and effort, which can be clearly seen in disability narratives (Dunn & Burcaw, 2013). In addition, the difficulty of the development of pride among disabled people has been also explained by disabled people’s isolation in their own communities, which usually do not include other disabled people than the one with disability (Olkin, 2008). Therefore, these communities might fail to support the disability identity and pride (Bogart, 2014).

In summary, the investigation of the development of disability identity and pride is important in order to have a clear picture of disabled people, being far from prejudice in ableist societies regarding disabled people.

2.5.Disability, Body Image, Sexuality and Self-Concept Research in Turkey

Although there are numerous studies conducted with non-disabled Turkish samples on the dual or triple relationships between body image, sexuality, and self-concept, the number of studies conducted with disabled Turkish samples is very limited. The majority of the studies conducted with people with physical disabilities focused on the levels of self-esteem in regarding to their body image compared to their non-disabled peers or their peers with different disabilities (see Gürsel & Koruç, 2011; Kaner, 1995; Kaner, 2000). However, the results of these studies have yielded inconsistent findings on the relationship between body image and self-concept among disabled adolescents and adults, indicating the need for better understanding of this issue. Similarly, the literature on sexuality of people with physical disability is very scarce and is mostly based on the medical model of disability, investigating the effects of impairments on the sexual esteem, sexual behaviors, and sexual pleasure (see Akkuş & Duru, 2011; Altuntug, Ege, Akın, Kal & Sallı, 2014; Çelik et al., 2013). These studies consistently revealed the negative effects of impairments on the sexuality. Similarly, a review study conducted by Elbozan Cumurcu, Karlıdağ, and Han Almış (2012) documents the troubles that people with physical disabilities experience because of their functional limitations and the psychological effects of the problems with sexuality. In line with this, Özkorumak (2009) points out the role of medical staff and provides four levels of intervention for the doctors to use with their patients with chronic diseases while discussing sexuality. However, none of these studies focuses on the lived experiences of disabled people.

3. Aims of the Study

To the author’s knowledge, there is not any study conducted to investigate the development of disability identity or pride with a Turkish sample. In fact, the relatively scarce literature on the relationship between disability, body image, sexuality, and identity has shaped the aims of the current study. Therefore, the current study aims to shed a light to the self-concept development of Turkish people with physical disabilities in relation to their body appearance and functionality. Particularly, their experiences of romantic relationships and sexuality will be investigated. In the end, this study attempts to generate a theory and find the core component of self-concept development of disabled people in Turkey.

4. Research Question

How does the experience of disability regarding the appearance and functionality of the body affect disabled people’s relationships with self and others, mainly their romantic relationships and sexuality?

CHAPTER 2

METHOD

1. Methodological Background

There are several reasons why qualitative research was preferred over quantitative research; and why grounded theory was preferred over other qualitative research methodologies for the current study. First of all, the literature on psychological effects of having a physical disability has been very scarce and has been mostly based on quantitative studies, especially in Turkey. Although quantitative studies provide hard, reliable, and generalizable data, and are an important source to confirm related theoretical notions on the topic under investigation, they are not concerned with having rich and deep data from an insider's perspective. On the other hand, qualitative research provides exploratory concepts and theories based on the detailed accounts of the participants (Bryman, 1988), which helps the researchers to make sense of the participants' inner experiences on a particular topic, or to investigate the role of social dynamics on their personal lives (Starks & Brown Trinidad, 2007). Since critical realist approaches to disability defines disability as a multi-factorial concept with its biological, social, cultural, political, and psychological aspects which constantly interact with each other (Shakespeare, 2014, pp.72-91), the need of understanding physical disability from the perspective of the people who experience it within their own environment grows. Therefore, the lack of culture specific understanding of the psychological effects of having a physical disability which requires the use of wheelchair in Turkey has created the need for choosing a qualitative methodology for this study. As a result, for the current study, grounded theory was chosen as the most suitable methodology among other qualitative research methodologies.

Grounded theory, which was developed by Glaser and Strauss (1967) during their study on the awareness of dying, is a qualitative research methodology aiming to understand individuals’ social interactions with others and the meaning of these interactions within the context they are experienced. That is, grounded theory aims to conceptualize participants’ stories that are narrated on the subject of investigation (Pidgeon, 1996; Mills, Bonner, & Francis, 2006), which enables the researcher to include facts that might be overlooked in other methodologies, and to develop an explanatory theory through the usage of systematic and powerful methods (Rennie, Phillips, & Quartaro, 1988). This is achieved through inductive examination of the qualitative data gathered from different sources such as semi-structured interviews, field observations, and bibliographic materials. Among many approaches to grounded theory, constructivist approach posits that during studying basic social processes, there is no objective reality, but instead, the reality is constructed through social interactions, including the one with the researcher (Charmaz, 2008). That is, in constructivist grounded theory, the data collection and data analysis processes are affected by the researcher’s interpretation of the phenomenon under investigation. Therefore, the constructed theory is the product of the interpretations of the participants’ accounts by the researcher. This is why, the researcher’s reflexive stance to their own presuppositions is crucial for understanding their own role in constructing the theory (Charmaz, 2006, pp. 129-131). In the light of this information, grounded theory was preferred over other qualitative research methodologies for the current study because it has enabled the examination of the effects of social structures of Turkish society on the personal experience of having a physical disability. In other words, grounded theory has given the researcher the possibility to develop an explanatory theory on the both psychological and social processes related to being a wheelchair user in Turkey, which hasn’t been well-documented in the literature yet, and to determine culture-specific aspects of living with physical disabilities for future studies and interventions in the fields of clinical psychology and disability studies.

2. Participants and Sampling Method

The sample of the study consisted of ten individuals with physical disabilities. The inclusion criteria were initially determined as follows: a) being older than 18 years old, b) having a physical disability as a result of congenital or acquired conditions, c) being a full-time wheelchair user, d) not having any other sensory or intellectual disability, and e) living in Ankara (to conduct the interviews face-to-face). However, as the data analysis continued, another criterion was added to the list: living apart from the family, either alone, with friend(s), with an assistant, with a partner or spouse, or with children. In other words, the participants were reached through theoretical sampling method, in which the subsequent participants are decided based on the analysis of previously collected data in order to move towards constructing a theory. Therefore, the researcher continued to search for participants until the theoretical saturation was achieved, meaning that the constructed theory is fully grounded in the data (Glaser & Strauss, 1967). Moreover, other factors such as restricting the type of disability under investigation to only physical disabilities which require becoming a wheelchair user, using one-to-one interviews as a means of collecting data, and having detailed responses from the participants not only about their own but also about others' experiences influenced the sample size. As Morse (2000) suggested, sample size in qualitative studies is evaluated based on the scope of the study, the nature of the topic, quality of the data, study design, and the use of shadowed data. In fact, the sample size of studies conducted with grounded theory ranges between 10-60 participants (Starks & Brown Trinidad, 2007). In this sense, the sample size of the current study was in line with the sample sizes of typical grounded theory studies.

The participants were men (n = 5) and women (n = 5) with physical disabilities, within the ages between 21-65 years old , from middle-low (n = 3), middle (n = 4), and upper-middle (n = 3) classes, and with different types of disabilities that require them to use either manual or electric wheelchairs (see Table 1 for the details). None of the participants has sensory or intellectual disability. Out of 10 participants one of them is a high school student, one of them is a high school graduate, and others are university graduates. 8 participants have either part-time or full time jobs, whereas one participant was retired due to his disability. 5 of the participants currently live with their parents, 3 of them are married and live with their partners, and 2 of them live alone at their own houses. One of the married participants has also a formal personal assistant who provides support for the participant's basic daily needs, such as getting dressed, using bathroom, cooking, and cleaning.

Table 1. The Demographic Characteristics of the Participants

Name	Age	Education	SES	Type of disability	Residence
Hakan	29	University	Middle	Spinal cord injury – at 20 years old	w/ parents
Hande	29	University	Upper M.	Spinal cord injury – at 17 years old	w/ parents
Burak	45	High school	M.-low	Multiple sclerosis – at 34 years old	w/ parents
Ömer	44	University	M.-low	Cerebral palsy – congenital	w/ parents
Aslı	21	High school	M.-low	Spinal muscular atrophy - congenital	w/ parents
Fatih	65	University	Upper M.	Spinal cord injury – at 43 years old	w/ partner
Işıl	39	University	Middle	Muscular dystrophy – at 19 years old	w/ partner
Ülkü	37	University	Middle	Muscular dystrophy – at 5 years old	w/ partner
Doğan	54	University	Upper M	Spinal cord injury – at 29 years old	Alone
Damla	27	University	Middle	Brittle bone disease - congenital	Alone

3. Procedure

The ethical permission of the study was taken from Human Subjects Ethics Committee of Middle East Technical University (No: 2015-SOS-170). The participants were initially contacted via phone or e-mail (see Appendix A for the announcement of the study). During this first interaction, information regarding the aims of the study was given to the participants, and their oral consent for the participation was taken. The interviews took place in quiet and calm places, such as coffee shops, that the participants preferred according to their accessibility needs and they lasted between 45 and 116 minutes, with a mean of 82 minutes. The interviews started after the participants were informed about the study (see Appendix B for the informed consent form), data collection process, confidentiality, and voluntary participation; and their written consent was obtained. A semi-structural interview was conducted with each participant, starting with demographic information and a general question to warm up the participants to the interviews (i.e. the effects of having a disability on their lives, see Appendix C for the first set of questions). The rest of the interviews were shaped by the participants’ own agenda related to their body appearance and functionality. During the interviews, they were encouraged to talk freely about their personal experiences. Therefore, topics like having constant support from others, romantic relationships and sexuality, marriage, having children, and social prejudice about disability and bodies with impairments were discussed. The question set was not the same for all the participants, because some questions were omitted and some others were added as a result of the analysis of each interview, as it is suggested for grounded theory methodology (Glaser & Strauss, 1967). All of the interviews were recorded and were transcribed verbatim by the researcher for data analysis. In order to ensure the anonymity and confidentiality of the participants, identity revealing information was changed while transcribing the interviews and reporting the results.

4. Data Analysis

During the analytic process, as it is suggested by Charmaz (2006) for grounded theory methodology, each interview was initially coded line by line in order to stay close to the data during later analysis. Following, the codes were analyzed and were grouped into meaningful categories; which is a process called focused coding and which is helpful to have insight about the theory grounded in the data. As the analysis continued, constant comparison methods were used in order to find similarities and differences within and between the participants. In parallel to this process, memos were regularly written about the categories that were formed in order to have more insight about them since they would become the components of the theory. With the help of this method, the definitions of the categories and the relationship between them became more apparent. The same process was followed at the end of each interview, which created an interactive and iterative process between data collection and data analysis. These iterations enabled the researcher to come up with new ideas and questions to address during subsequent interviews. At each level of the analysis, MaxQDA, qualitative data analysis software, was used (Verbi Software, 2005).

5. Trustworthiness of the study

The trustworthiness of qualitative research can be achieved and can be increased through the use of several methods. Smith (1996) suggests that internal coherence, presentation of evidence, independent audit, triangulation, and member validation are important tools to assess the trustworthiness of qualitative research. Moreover, the use of memos while conducting grounded theory studies increases the trustworthiness by functioning as an audit trial for the researchers, by which the researchers can follow their own thoughts and reactions about the phenomenon they study (Cutcliffe, 2000).

In line with the suggestions in the literature, as the researcher of the current study, I was concerned about the importance of consistency and coherence during the analysis and the reporting of the participants' accounts rather than the representativeness of the sample. After I individually completed the data analysis, I discussed the results with a group of clinical psychologists who are also experienced in qualitative research, with a group of activists who work in disability field, and with two of the participants of the study. At the end of these discussions, I revised the first drafts of the theory according to their suggestions; and my thesis supervisor and other members of my thesis monitoring committee audited the whole process until the theory was constructed. Moreover, while reporting the results, I paid attention to present the different components of the constructed theory with evidences from the interviews to increase the credibility of the analysis by allowing the readers to take part in the dialogue with the data. Lastly, I wrote memos from the beginning until the end of data collection and data analysis processes to make sense of my thoughts and feelings elicited by the interactions I had with the participants. This method helped me a) to become more aware of my presuppositions and experiences, especially as a person with disability, regarding the emerging themes and categories about the psychological effects of having a physical disability in Turkey, and b) to conduct the analysis by bracketing my own material. In the literature, it has been argued that each researcher can formulize his or her role differently based on the theoretical stance they hold. In the current study, I used reflexive (cultural) bracketing (Geiring, 2004), minimizing the effects of pre-existing suppositions about the topic under investigation on the research process by bracketing them out as much as possible. However, I also acknowledged that "external" suppositions, such as context, culture, and environment cannot be bracketed out, but can be included into the phenomenon. Following, as the researcher of the current study, I summarize my role in collecting, analyzing, and reporting the data.

6. Reflexivity

As a person with congenital physical disability, who was born and raised in Turkey, I have faced many physical and social barriers throughout my life – and my relationship with my condition has kept changing although physical and social barriers have remained mostly stable over time. As a consequence, I have always had inner conflicts about my disability, even though I have always looked calm and "well-adjusted" to my life with a disability. Most of these conflicts have resulted from the discrepancies between how I wanted to be and how I was in reality and have caused lots of difficulties in my interpersonal relationships. However, I haven't realized for a long time that the way how I wanted to be was shaped by the society's standards of beauty – and ability. What helped me to arrive to that conclusion were my undergraduate education in psychology, in which I learned to understand mental processes of human beings from a biopsychosocial approach, and my volunteer work in METU without Barriers, the university club of disabled students. During my active membership in this club, for two years of which I was the president, I had the opportunity to better understand social model of disability. Following, my graduate education in clinical psychology that emphasizes the importance of introspection and my professional experience as a clinical psychologist enabled me to have more insight about my inner life. This was the period of my life when I started to question everything I accepted as absolute facts, all of which were playing disabling role in my life along with the barriers in the society. Besides, I could also start understanding the psychological and social reasons for internalizing everything without questioning. These realizations helped me to make decisions that increased my independency. Moreover, I started to have an active role in organizations working to ensure the rights of disabled people, such as Association of Women with Disabilities in Turkey, and European Network on Independent Living (ENIL), both of which contributed me to become a disability rights activist.

My personal experience as a disabled person, my education in psychology, my professional experience as a clinical psychologist, and my interest in disability studies and disability activism had an influence on this research process, from the beginning to the end. First of all, the formulation of the research question was based on my personal experiences of disability as well as my academic knowledge in appearance research and disability studies. However, my personal experience as a disabled person was both advantageous and disadvantageous while conducting the interviews. On one hand, some participants expressed that they felt very comfortable with someone who had similar experiences and therefore, who wouldn’t judge them. I also felt that they were really open and this also eased the interview process for me. On the other hand, some participants’ accounts were very familiar to me, which sometimes elicited sympathy during and after the interview. Similarly, some other accounts which didn’t reflect my point of view towards disability also triggered strong emotions. Although it was hard to manage those emotions during the interviews, they provided valuable information in the analysis. During the analysis of the collected data, the hardest part of the process was to generate a theory which brings together clinical psychology and disability studies, without dehumanizing or psychopathologizing the experience of disability by focusing solely on social or psychological factors, as my experiences summarized above demonstrated that disability is the combination of all these factors. Similarly, to find the balance between these two fields was a challenge during reporting the results, as well as to not use the language victimizing disabled people, which is actually one of the maintaining factors of ableism in the society.

My thesis supervisor, Prof. Dr. Tülin Gençöz, audited each step of this research, from the formulation of the research question to the reporting of the findings, as a senior clinical psychologist experienced in theories of personality and emotions. Therefore, she did not only help me to develop my ideas on the influence of separation-individuation process on the development of pride among disabled people, but also she enabled me to become more aware of my own emotions during the process and my own personal development as a disabled woman.

Overall, this study has widened my knowledge and experience in research in clinical psychology and disability studies, enabled me to combine two seemingly distinct fields of research and practice, helped me to better understand the inner lives of disabled people, and encouraged me to continue to strive for independence in my personal life.

CHAPTER 3

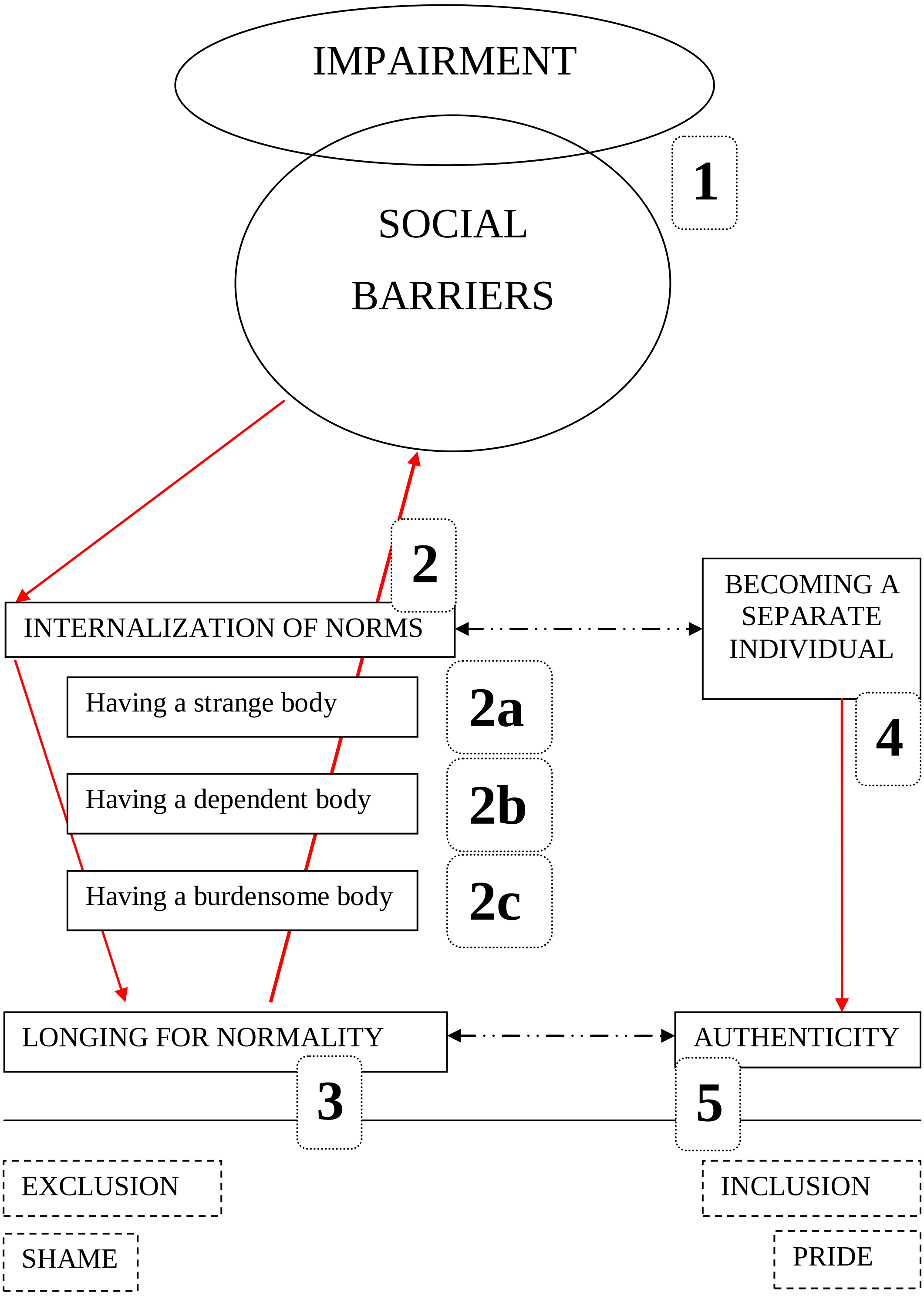
RESULTS

As it is illustrated in Figure 1, the experience of disability begins with the existence of impairments and social barriers, including physical barriers and attitudinal barriers, all of which are in interaction with each other (Category #1). As a result of this interaction, the norms with idealist and ableist societies are internalized by disabled people (Category #2) and they begin to perceive their own bodies as strange (#2a), dependent (#2b), and burdensome (#2c). Therefore, for those who have this kind of perception, having different body appearance and functionality becomes the source of the problems they face, and the longing for normality (Category #3) increases. In turn, this leads to the strengthening of social barriers, forming a vicious cycle between social barriers, internalization of norms, and wish for normality. On the other hand, questioning of the idealist and ableist norms in the society enables disabled people to become separate individuals (Category #4), which leads them to reach to their authentic selves (Category #5). These categories will be presented along with the participants' accounts and will be discussed based on the first route's relationship with exclusion and shame, and the second route's relationship with inclusion and pride in the next chapter. It is worth to note that personal experiences of disability influence everyone's path between internalization of norms and becoming separate individuals as well as the path between wish for normality to authenticity in various ways; and this variety will be mentioned throughout the results.

1. Category #1: The interaction of impairments and social barriers

This category describes the interaction between participants' physical impairments and existing barriers to their inclusion in the society, including physical barriers and

Figure 1. The experience of disability in relation with internalization of norms and becoming a separate individual



attitudinal barriers in the society. Impairments and social barriers are the only external realities in the proposed model, though impairments cannot be and don't have to be changed whereas social barriers can be and should be changed in order to ensure the inclusion of disabled people in the community equally with others.

The first element of this interaction is the presence of congenital and acquired impairments, which are described roughly by the diagnosis that disabled people have since the onset of their disability. These diagnoses are associated with some functional limitations such as inability to walk, inability to use arms effectively, inability to sit for long periods of time, and inability to control bladder (especially for individuals with spinal cord injury), all of which are the results of the loss of sense and strength in different parts of their bodies. For people with physical impairments, these limitations complicate the completion of some daily activities on their own, for which they rely on other people, such as eating, getting out of the bed, dressing up, using toilets, and taking bath. The onset of the disability (either congenital or acquired in a sudden or gradual ways) influences the ways how these limitations are perceived. For instance, Ömer (44), who has cerebral palsy since his infancy due to wrong medical interventions, explains his impairments as:

> "**Ömer**: Kasıntılarım var, sadece kol ve bacaklarda. O kadar. Onun dışında hiçbir sorun yok. […] Her işimi ağzımla yapıyorum, yazılarımı ağzıma aldığım kalemle kafa hareketiyle yapıyorum. Eşyaları oradan oraya ağzımla taşıyorum. […] Ama ne olursa olsun ikinci bir kişiye birçok şeyde muhtacım, yani, ihtiyacım var.
> **Researcher**: Peki, küçüklüğünüzden bu yana rahatsızlığınızın nasıl bir seyri oldu?
> **Ömer**: Ben hayatı böyle bildim. Benim çocukluğumda hiçbir 'aman, şunu yapıyordum, bunu yapamıyorum, şu duygudaydım, bu duyguya geçtim' diyemem ki. Benim hayatım hep böyleydi. O yüzden benim için bir farklılık yok."[1]

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[1] "Ömer: I have contractions, only in my arms and legs. That's all. There isn't any other problem. […] I do everything with my mouth, I write my articles by moving my head with a pen in my mouth. I can carry things from there to here. […] However, I am dependent to others for many things, I mean, I need them.
Researcher: So, how was the prognosis of your condition since your childhood?

Similarly, Aslı (21), who has a congenital neuromuscular disease, states her thoughts and feelings about her impairment as:

> "… kabullendiğim zaman, bir süre sonra beynime onu oturttuğum zaman her şey normale dönüyor: Ben de böyleyim, diyip kendimi bir şekilde kendimce şey yapıyorum. İlla ki her türlü zorluğu var ama artık doğuştan beri böyle yaşadığım için onlar belli bir süre sonra normalleşiyor."[2]

These quotations illustrate how people with congenital and early-acquired disabilities see the reality of their bodies as their own normal, since they have no experience of being non-disabled at any point of their lives. Therefore, the presence of physical impairments that causes limitations or that require help from others is integrated to their senses of self. On the other hand, when impairments are acquired in a sudden or gradual way, people experience a shift from one reality to another, which is associated with feelings of loss. For example, Hakan (29), who has spinal cord injury due to an accident at the age of 20, describes his changing sense of self as follows:

> "Üniversitede okurken trafik kazası geçirdim. Ondan önce sağlıklıydım. Eğitimimin ortasında o başıma gelince, boynum kırılınca, omurilik felçlisi oldum. […] Daha öncesinde her işini kendi yapan, sabah kalkıp okula giden, dersi olduğunda okula giden, gelen, çalışan ve engellilik kavramıyla hiç tanışmamış biri olarak herkes gibi hayatını normal geçiren biriydim. Ama o kazadan sonra her şey çok değişti."[3]

In other words, prior experiences of "being normal" shape his understanding of his disability. What is lost here is his ability to take care of himself without needing

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Ömer:I have known the life like this. I can't say things like 'I used to do this in my childhood, I can't do now, or I was feeling this emotion, I moved to another one'. My life was always like this. That's why, there is no difference for me."

[2] "…when I can accept it, when I can instill it in my mind, everything becomes normal. I say 'I'm like this' and I'm just keeping myself in my own way. Of course, it brings lots of problems but because I live that way since my birth, they become normal after a while"

[3] "I had a traffic accident when I was a university student. I was healthy before. When this happened during my education, when my neck was broken, I had a spinal cord injury […] Before that, I used to be someone who could do everything on his own, wake up and go to school when there was a class, come, work, and spend his life normally as a person who has never met with the concept of disability. However, everything changed after that accident."

help from others unlike his prior experiences. This is why people with acquired physical disabilities are faced with the challenge of adapting to a new reality regarding the needs of their bodies and the ways to meet them.

Moreover, since the onset of their disabilities, participants have been under medical surveillance and treatments, or have been going through physiotherapy on a regular basis in order to maintain or to ameliorate their current conditions. It is stated that some of these rehabilitative practices are helpful at the beginning of an acquired disability, aiming to introduce assistive devices that will increase the mobility of people who have recently became disabled. However, for some, the rehabilitation process goes on for years. In one way, it is seen as something necessary at least to maintain their current physical condition; in another way, they do not always produce the expected results. For instance, whereas Doğan (54), who has spinal cord as a result of traffic accident at the age of 29, states that he has adhered to the suggestions of his doctors in order to prolong his life since his injury, Işıl (39), who has a muscle weakness since her university years, expresses her helplessness towards her progressive disease:

> "… hastalığımı stabil bir düzeyde tutmam lazım ama bu benim elimde değil. Bu da bir stres, benim elimde değil. İşte, hareketler falan, işte, […] işten çok yorgun geliyorum. […] Bir iki yapıyorum ama her gün değil yine. Her gün aynı stabillikte sen egzersiz yapamıyorsun, yorgun hissediyor vücudun. Artık yapabildiğim sürece biraz bir şeyler yapmaya çalışıyorum ama yine bakıyorum, ilerliyor, yapacak bir şey yok. Artık bunu böyle kabullendim"[4]

In addition, having regular physiotherapy sessions might become something that points out the difference from non-disabled others, who do not necessarily have such a routine. As Hande (29), who also has spinal cord injury due to an accident at the age of 17, states:

> "…bunlar zaten bayılarak yaptığım işler değil, sen benim arkadaşım görünüyorsun, yani, cuma günü uygun olmadığımı, hem de sağlık

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[4] "I have to keep my condition in a stabile level but it's not in my hands. It's another source of stress, it's not in my hands. Like, exercises… […] I come from work very tired. […] I'm trying to do some exercises, but you can't do it constantly every day. Your body is tired. I am trying as much as I can do but then my condition keeps progressing. There is nothing to do. I accept it that way."

> sebebiyle bil. Niye bunu bilmiyorsun? O zaman insanlara biraz negatifleşmem başlıyor. Tamam, bana normal insan gibi davranın ama gerçekliğimi de reddetmeyin. Yaşadığım bir gerçek var sonuçta, bunu reddedemem ben yani. Ben o kadar bağımsız değilim, her aklına estiğinde çıkabilen biri değilim."[5]

As it can be understood from the quotations above, the meaning that is given to impairments and treatments changes from one person to another. However, if there is one thing that all participants share, it is the presence of social barriers in Turkey. In fact, most of the participants define those physical and attitudinal barriers in the society as "usual problems of the disabled", preventing them to fully participate to the society. Physical barriers include lack of accessible buildings, restaurants, and other public spaces with accessible parking space and accessible toilets, lack of accessible transports, and lack of systematic support. In fact, Aslı, who has a congenital neuromuscular disease as stated above, and Damla (27), who has brittle bone disease, compare physical accessibility in Ankara to that of other cities, such as Gaziantep and Eskişehir:

> "Gittiğin yerleri seçmek durumundasın. Şuradan şuraya kadar metroyla giderim, orada merdiven var mı, üst geçit var mı, üst geçidin asansör var mı? Her şeyi düşünmek gerekiyor. O da ister istemez insanın dışarı çıkasını… bazen, aman şimdi kim uğraşacak diyip vazgeçtiğim de oluyor. Ama Ankara'da böyle. Ben mesela, Antep'e gitmiştik, orada gayet otobüsler falan, her yer o kadar engellilere göre ayarlanmış ki… Kaldırımların kenarlarında bile, hani bisiklet gibi, engelli arabalarının geçmesi için yerler yapılmış. Ondan sonra mesela çok şaşırdım, duraklarda akülü araba şarj etme şeyleri var. Ankara'da ben daha, kocaman başkentte yaşıyoruz, büyükşehirde yaşıyoruz, hiç görmedim yani. Her şey kısıtlanıyor bir şekilde. Bu sosyalleşmeyi de engelliyor." (Aslı)[6]

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[5] "I don't love doing these, and you look like a friend, so, you have to know that I'm not available on Fridays, because of health issues. Why don't you know this? Then I get angry with people. OK, behave me like I'm a normal person but don't deny my reality. This is my reality, I can't deny this. I'm not that independent, I'm not someone who can go out whenever she wants".

[6] "You have to choose wherever you go. I can go there by metro, are there any stairs, is there a bridge there, is there an elevator on the bridge? You have to think about everything, and it influences people's wishes to go out… I sometimes say, I can't deal with this now and I give up. But this happens in Ankara. In Gaziantep, everything is arranged for disabled people, the buses and everything… There are ways for wheelchairs at the side of the sidewalks. I was really surprised to see that there were charging units for electric wheelchairs. I have never seen those in Ankara, although this is the capital city. Everything is restricted somehow. This limits socialization"

> "Ama Eskişehir çok erişilebilir bir şehir. Burada yaşadığım hiçbir sorunu ben orada yaşamıyorum. İstediğim her an istediğim her yere gidebiliyorum çünkü her şey engellilere uygun. Olmayan bir şey yok. Hani ya, şuraya da gidemem, bura da sıkıntılıdır dediğim bir şey olmadı. Hep kenarından köşesinden mutlaka bir düşünülmüş, yapılmış şeyler gördüm orada" (Damla)[7]

Therefore, as it can be understood from these quotes, the lack of accessibility becomes the main problem in being equally included in the community for disabled people. With all these physical barriers in the society, there are fewer opportunities and options for disabled people. In fact, these barriers limit their lives more than impairments do, because actually, they are the reason for staying at home. On the contrary, accessible public spaces and transports enable disabled people to fully participate to social life as an equal member of the society, which actually can play a buffering role against negative effects of impairments.

Attitudinal barriers in the society are the second type of barriers in the society that has a great impact on the lives of disabled people. These barriers refer to the reactions that disabled people get from others, who range from total strangers to family members. Although not everyone gives problematic reactions when they relate with someone who has a visible physical disability, some experiences are commonly mentioned by disabled people, such as being stared, commented on, or questioned about their disabilities by strangers. The content of these reactions is not always negative. For instance, Fatih (65, who has spinal cord injury for 21 years) states: "*Yani, engellilere insanların bakış açısı çok değişik. Kimisi üzülerek bakıyor, kimisi acıyarak bakıyor, kelimeleri seçmekte zorluk çekiyorum. Üzülerek, acıyarak, Allah beni korusun diye kendine şey çıkartarak, bazıları da gösterdiğim gayrete hayretle ve takdirle bakıyorlar."*[8]. These reactions are the results of the way how

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[7] "But Eskişehir is very accessible. There, I don't face the problems I face here. I can go anywhere I want at any time because everything is arranged for disabled people. I have never thought something like 'I can't go there' because everything were already arranged"

[8] "I mean, others' perspectives to disabled people are very strange. Some of them are sad for us, some of them have a pitying look, it's hard to choose words. Sad, pity, some of them say 'God forbid me from this', and some of them appreciate the effort I have been making."

disabilities and disabled people are seen by non-disabled others. In fact, participants believe that these reactions reflect personal processes of non-disabled people, and that is why it changes from one person to another even if their disabilities do not change. Moreover, people with congenital or acquired disabilities express that they get used to these reactions with time. However, this does not change the fact that these reactions are sometimes perceived as violations of personal boundaries. For instance, Aslı expresses her frustration towards some comments and questions that she gets at unexpected moments as follows:

> "**Aslı**: İnsan mesela, dışarı çıkıyorsun, arkadaşlarınla oturuyorsun falan böyle, en olmadık bir anda biri geliyor "Kızım, geçmiş olsun" diyor mesela. İşte, "doğuştan mı?" diye soruyor. O an, o ortamda onu anlatmak insana böyle hani, gocunduğum için değil de o an o psikolojiyi… İster istemez düşürüyor enerjini de. Hani, öyle ortamlarda sinir bozucu oluyor sadece.
> **Researcher**: Enerjini düşürüyor derken?
> **Aslı**: Moralimi bozuyor, moralim yüksekken. Durup dururken, onu hatırlatması, "hiç sırası değildi" diyesi geliyor insanın. Öğreneceksin de ne olacak, doğuştan veya sonradan. Sana ne gibi bir getirisi var?"[9]

Hande also believes that negative comments about her disability either from strangers or from friends and family members have a very negative influence on her psychological well-being:

> "Benim bir teyzem vardır, hemen ağlar bazı şeylerde. Çok sever, çok üzülür, ama ben o teyzemin ağlamayı sevdiğini düşünürüm çünkü bu teyzem benim için de ağlar ama alışveriş merkezinde olsak ve beni tanımasa asansörde bana yol vermeyecek bir teyzedir. Yani, üzülmeyi seven bir halkımız var, insanlar var, dünyada da var. İşte, o

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[9] "Aslı: For example, you go out with your friends, and someone approaches at the moment least expected and says 'get well soon', or asks whether it is congenital. At that moment, you're not offended by the question but your mood is… Your energy is lost. It is just annoying at these moments.
Researcher: What do you mean you lose your energy?
Aslı: It gets me down, while I was high. For no reason, reminding me of that, I'm like 'it wasn't the right moment'. What will happen when you know if it's congenital or acquired, what you will get from that?"

> insanlar negatif bir etki yapabiliyorlar, benim isyanımı da arttırıyorlar."[10]

These quotes demonstrate that non-disabled people in Turkey do not have awareness on disability issues and also, they are inclined to see disability as a personal tragedy. Furthermore, for these people, disability is a tragedy because they think the lives of disabled people are restricted because of their impairments. In other words, they believe that the presence of impairments is the main reason for leaving school or work, for staying at home, for not socializing, or not having romantic relationships. Besides, because there is a lack of understanding of right-based approach to disability and the ableist comments are very common in the society, nearly everyone, including close friends and close family members of disabled people, conveys such ableist messages to disabled people. Therefore, disabled people are born with impairments or become disabled in a society where the norm is being non-disabled. As a result, these norms are easily internalized and this becomes another barrier to the empowerment of disabled people.

2. Category #2: Internalization of Norms

Being raised in an ableist society as a disabled person or becoming disabled after being exposed to such ableist norms has a negative influence on understanding disability as an integral part of self. As non-disabled others impose on them, disabled people might develop an idealist and ableist point of view, not necessarily towards their own selves but at least several aspects of their selves. Although the presence of non-disabled and disabled people who can challenge these idealist and ableist norms has buffering effect on their lives, which will be examined in more detail in the following sections, the negative effects of internalized ableism is prevalent among disabled people. For instance, Burak (45), who was diagnosed with multiple sclerosis 11 years ago, realizes that he might be the one who distances himself from others, even though others might actually be accepting:

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[10] "I have an aunt, she cries easily. She is very sad but I believe she likes crying because she also cries for me but if we were in a mall and never met, she wouldn't let me get in the elevator. So, our people love crying – but these people negatively influence me. They increase my anger"

> "Çıkıyorum sandalyemle caddeye, tamam ama, biraz da ben şey yapıyorum sanki… bir an önce onların yanından uzaklaşayım da, engelimi belli etmeyeyim. Belki onlar hiç gitmemi istemiyorlar, 'gel gel' diyorlar, belki gitmesem, kalsam, daha iyi anlayacaklar, konuşacaklar. Biraz da ben onlarla konuşmak istemediğimden, anlatmak istemediğimden. Zamanında ben cebimde paralar, banka cüzdanları… Yürüyorum, gidiyorum. Şimdi bununla… Önceden hep elim cebimde. Belki onlar beni kabul ediyorlar ama eksiklik bende, ben kendime yediremiyorum, kabul edemiyorum."[11]

This quote reflects how having a progressive disease that causes disability can change one's perception of self through previously internalized assumptions about disabled people. To be more precise, with these internalizations, acquiring a disability is associated with a meaning more than losing the ability to walk. In Burak's case, it is associated with losing his social status. Actually, this aspect of understanding disability is largely influenced by gender roles in the society. Similar to Burak, Hakan feels that he is not very effective in decision making processes at work because of his disability:

> "Biraz ataerkil bir toplumuz, erkeklerin karar verdiği, bir şey yaptığı, herkesin ondan bir şey beklediği bir durum aslında. Onda biraz arka plana atıldığımı… Hem ben yetişemediğim için arka planda kalıyorum. Hem de insanlar çok önemli meselelerde farklı insanlarla yürüyor. Benim de bir katkım oluyor, ama çok sert değil. Mesela bir müdür olup her işe şey yapamam ben diye düşünüyorum, ya böyle hissediyorum ya da engelli olduğum için geri planda duruyorum, […] izleyici konumunda kalıyorum. Fikirlerimi söylüyorum, ama arkasında duramıyorum mesela."[12]

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[11] "I go out with my wheelchair, but I think I'm more like… I want to leave others without revealing my disability. Maybe they don't want me to leave, they call me over, maybe if I stay, they will understand me better. They will talk to me. It's because I don't want to talk with them, I don't want to explain. I used to have lots of money in my pockets. I used to walk and go. Now with this… My hands used to be in my pockets before. Maybe they accept me but I have the deficiency, I can't accept myself like this"

[12] "We are a patriarchal society, in which men make decisions, do things, and everyone expects something from them. I am pushed behind in these situations. I myself stay behind because I am not adequate, and people prefer others in important issues. I also have a contribution but it is not hard enough. For example, I think I can't be a manager and take care of everything. I either feel that way or I stay behind because I'm disabled. […] I'm an audience. I state my opinions but I can't defend them"

Therefore, the presence of a disability might interrupt the process of meeting society's expectations, which include deciding, managing, and being assertive for men. On the other hand, women are more concerned with their appearance and their ability to do housework. For instance, Hande explains her difficulty to be seen and to see herself as an attractive woman with her wheelchair: "*Kızın boyundan aşağı süzer,* […] *bende ondan çekindiklerini hissediyorum,* […] *genelde çekinirler, gözlerini kaçırırlar. Tamam, yapmasınlar ama onun sebebinin engelim olduğunu biliyorum. Daha… 'Yazık' konumunda olduğum için…"*[13]. However, Işıl expresses her concerns before she got married as follows:

> "Hani bir kas hastasıyla hiçbir insan hani cesaret edip evleneceğini düşünmüyordum. Çünkü biz daha bağımlıyız daha sınırlıyız. Kadın ve erkeğe evlilikten sonra sana düşen şeylerin çoğunu yapamıyoruz. Bir de çocuk konusu. Çok önemli bir konu. Allah'tan eşim çocuk istemiyor. Evlenmeye soğuk bakma nedenlerimden biri buydu. Ailem hep şunu diyordu: çocuk ister. Hani Türk aile yapısı, evlenince ne olur? Çocuk olur. Çocuk yapamazsın. Yani, erkek, çocuk istiyor. Olmaz hakikaten. Ben de çocuk doğurabilmek, benim için de zor gibi geliyor. Hastalığımızı zaten ilerletecek, o sıkıntı da, erkek de çocuk isteyecek, bu bile sorun olacak."[14]

In other words, according to the mainstream culture in Turkey, women with disabilities cannot meet the expectations to do housework and to raise children. Therefore, disability interrupts women's role of being attractive and providing care to others in the family, which puts them in a position where they question themselves instead of questioning the societal norms. All of these experiences results in the feelings of inferiority compared to non-disabled people in many areas of life, which actually has a complementary effect to the prevalent understanding of

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[13] "For example, they eye other girls from head to foot, I feel like they feel uncomfortable doing this with me. They usually do, they turn their eyes away. OK, they shouldn't give me the eye but I know that the reason for this is my disability. It's because I'm in a position that they pity."

[14] "I was thinking like no one would dare to marry someone with muscular diseases because we are more dependent, more limited. We can't do most of the things that men and women are expected after getting married. And the problem of having children, it's very important. I'm lucky that my partner doesn't want one. This was one of the reasons why I used to be cool towards marriage. My family always said: What if he wants a child? This is Turkish family structure. Giving birth would be difficult for me, and it has a progressing effect on my disease. If a man wants a child, it's a problem."

disability as a personal tragedy. In fact, this is how a charity culture, in which disabled people are seen as the passive recipients of help from non-disabled others who, in turn, feel better just by providing aid to those in need, is maintained. Because of the internalization of ableism, disabled people might fail to realize the possibility of other ways to relate with non-disabled others and to request it from them, as it can be seen in the following accounts of Ömer:

> "Hani, biz çocukken tatillere giderdik, mısırcılar mısır hediye ediyordu. […] Aslında o iyi niyetiyle, yapabileceği yardımını yapıyor aslında. Yardım derken, beklentisel değil, manevi duygusunun yardımını yapıyor. Mesela biz bunları kabul ederiz. O diyalog esnasında, o adamın samimiyetine bağlı olarak, hani, "bende bu var, ben bunu vermek istedim, çok sempatik geldi, benden olsun" derse, çünkü bu… onlar da o tatmini yaşamak zorundalar. Zaten bizimle iletişimleri, bunlar yapıldığı sürece sağlıklı olur"[15]

Here, it can be seen how the internalization of ableism and other assumptions regarding disabled people lead Ömer to define a relationship as healthy when it puts disabled people in a passive position. As a result, he accepts the position he has been given and does not request from non-disabled people a different way of relating with himself and other disabled people.

Body is the main site where ableism is targeted; therefore, the internalization of idealist and ableist norms mainly affects the perception of body. Following, the three different perception regarding bodies with impairments as a consequence of the idealization of non-disabled bodies will be presented, respectively disabled people's beliefs that they have a strange body, a dependent body, and a burdensome body, all of which have substantial effects on their relationships with others and with their own selves.

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[15] "We used to go to vacations when I was a child, corn sellers would give me free corns. Actually, they were helping as much as they can with good intentions. Here, they don't expect anything, it's just their morality. We accept these things, during that conversation, based on their intimacy, if they say 'I have this, I wanted to give it, he's look so sympathetic, and it's free'. They have to have that satisfaction. Their communication with us is healthy as long as they can do this."

2.1.“… because I have a strange body”

In the case of acquired disabilities, one of the challenges for disabled people is to adapt to the new appearance of the body. This process is not same for everyone. However, either congenital or acquired, people with visible disabilities have the common experience of being stared at by the strangers, which leaves them with the feelings of being different from non-disabled others, as Aslı expresses in her following account: “*Hani bakıldığı zaman diğer insanlardan farklı olduğum gayet açık bir şey. Farklı hissediyorum, çünkü gözle görülen bir şey. Farklı hissetmemem mümkün değil. İnsan… Hissetmesem bile zaten insanların bakışları, onun farkındalığını veriyor zaten*.”.[16] This feeling is strengthened through the underrepresentation of bodies with impairments in the mainstream media and culture. For instance, Damla explains how difficult it is to find clothes that fit her different body type, resulting from brittle bone disease, and how it affects her sense of self:

> “**Damla**: Kıyafet bulurken aman orasını mı kessem, burasını mı bilmem ne yapsam? Hiçbir şeyi hiçbir şeye uyduramadığım dönemlerim oldu, hatta çocukken hep örgü giyerdim çünkü hani yok. Teyzem halam dikerdi, dışarıdan bir şey bulamıyorduk. Şimdi şimdi bulabiliyorum, giyebiliyorum, yapabiliyorum ama hani o dönemlerde yaşadığım o kıyafet bulamama, belli bir kalıba kendimi oturtamama sıkıntısı, evet, bir dönem oldu.
> **Researcher**: Bu size kendinizi nasıl hissettiriyordu?
> **Damla**: Alışılmışın dışında.”[17]

Therefore, these quotes reflect how the structure of the society has an important effect on the development of sense of self. In this case, disabled people experience

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[16] “So, when you look at me, it’s obvious that I’m different than other people. I feel different because it is visible. It’s not possible to not feel different. People… Even if I don’t feel different, the looks of other people gives met hat awareness”

[17] “Damla: When I search for clothes, I’m always like ‘should I cut this from here, do something else to here?’. I used to have moments when I couldn’t match anything with each other. I used to wear knitted clothes, because there weren’t anything that suits me. My aunts used to knit for me because we weren’t able to find anything to buy. I can find now, I can wear, but I used to have troubles when there were nothing to wear.
Researcher: How did it make you feel?
Damla: Peculiar.”

difficulties in feeling that they belong to the society because they are exposed to messages from very different external sources that they have an important difference. Combined with other assumptions about disability, this difference gains a negative meaning that bodies with impairments are strange or weird and this is the reason why they cannot be accepted in the society. These negative evaluations about bodies with impairments are associated with choosing certain types of clothing for some disabled people. For instance, Hande states:

> "Her türlü istediğim şeyi giyemiyorum. Yani, güzel elbiseler giymek, oturma pozisyonundan ötürü etekler çok abes oluyor. O yüzden onları giyemiyorum. Ayakkabılar istediğim gibi giyemiyorum. Giydiğin şeyi gösteremiyorsun. Tabii, ortada moda yapacak değilim de, severim giyinmeyi, süslenmeyi. Onları yapamıyorum." [18]

Similarly, Damla states that she used to prefer not to wear skirts to hide her legs because she used to think that they looked weird to others. Moreover, some non-disabled people hold a segregating belief that disabled people should form relationships with other disabled people, because they will better understand each other, as Ülkü (37), who has muscular dystrophy since her childhood, and who is currently married to a non-disabled man, states:

> "Şey diyorlardı hatta. Aslında engelli biri olsa da evlensen falan. Şey diyorsun, olabilir, tabii ki olabilir de, yani, şey diyorsun hani, olabilir ama şu an sevdiğim kişi engelli değil, yani, ama olabilir tabii, ama değil. Şey diyorsun, beni sevemez mi, oraya çıkıyor aslında. Çünkü siz birbirinize benziyorsunuz, kategoriler. Kast, kast sistemi var ya."[19]

In fact, many participants of this study reveal that they are matched with other disabled people, even though they don't seem to share any other characteristics than their disabilities that people evaluate before starting their romantic relationships,

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[18] "I can't wear everything I want. Nice dresses, skirts look weird because of my sitting position. That's why I can't wear them. I can't wear shoes as I want. You can't show what you wear. Of course, I will not take the podium, but I like dressing up, but I can't do that".

[19] "They were saying things like 'I wish you could find a disabled person and get marry'. Then you're like, of course, of course this can happen, but the person I like now is not disabled, he could have been but he's not. Then you say, he can't love me? Because this means that, because you look like each other, categories, or the cast system, you know…"

such as cultural background, interests, and personality. Furthermore, as it is referred as a cast system in Ülkü's accounts above, for some non-disabled people, being a member of disability community is being at a lower social status, and therefore, disabled people get the impression that they are not perceived as people who deserve non-disabled people as their partners and this is why they are matched with other disabled people. Although it is not possible to objectively evaluate the correctness of this assumption, it can be seen that the negativity attached to having bodies with impairments is internalized by the disabled people themselves. As a result, their interpersonal relationships are influenced by the position they take in the society. Hande explains this situation with the following words:

> "Birisi dışarıdan hoş buldu seni ama aynı zamanda kafanda uyanıyor, senin engelli olduğunu görüyor o insan. […] Yani, internette tanıştığım insanlar beni bu şekilde görmezken benim cinsiyetime daha çok dikkat ederler. Yani, kadınlığım daha çok öne çıkar, farkında olurlar. Ama sosyal hayatta, normalde dolaşırken, cinsiyetsiz gibi bir şey olduğumu düşünürüm çoğunlukla […], toplumun öyle baktığını düşünüyorum, biraz ben de, kendim de şey yapıyor olabilirim, engelimden ötürü cinsiyetsiz bir halim oluyor."[20]

In other words, disabled people are likely to experience that their disability gets in their way of being perceived as a sexual being because of their internalizations of people's attributions to impairments and disabilities at the background. However, disabled people who are frequently exposed to this kind of messages from the society inevitably begin to behave in accordance with the expectations of non-disabled others. For instance, Hande further explains the reason why she might be desexualizing herself with her need to protect herself from disappointments which might occur as a result of society's attitudes towards disabled people. In fact, this expectation of disappointment is shared by many participants of this study. However, disability not only affects how people evaluate their appearance and sexuality but also what they believe they deserve in their romantic relationships. For

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[20] "Let's say, someone likes you, but you start thinking that he sees your disability. […] I mean, the people I meet online pay more attention to my sexuality when they don't see me like this. I mean, my womanhood becomes prominent, they are more aware of it but in social life, when I'm out, I think I am mostly desexualized. […] I think the society sees me this way, but maybe I'm doing the same because of my disability."

example, Ömer expresses how helpless he was feeling when he wanted to end his relationship with his ex-partner, who was a non-disabled woman:

> "Bir de sürdürmemin bir sebebi de (laughing) neydi biliyor musun? Toplumdu yine. Toplumdu, 'çünkü sen özürlüsün, seni sağlıklı birisi kabul etmiş, senin burnun havaya kalktı'. Doğal olarak sen ayrılmaya kalktığın zaman 'Ne o? Güzel kızı bulmuşsun, her şeyinle de seni seviyor, ayrılmaya hakkın olamaz, çünkü sen özürlüsün'. Ve o kız ne olursa olsun ya da o kişi, eee, konumu gereği çok düşük de olabilir, sadece fiziksel anlamda sağlıklı olması toplumun bakış açısında bir engellinin ondan daha düşük durumda olduğu için dedim ki "oğlum, senin ayrılmaya hakkın yok… Seni suçlayacaklar, sen ayrıldığın takdirde toplum seni suçlayacak". Engellilik sebebiyle, ayrılmaya hakkım yokmuş gibi hissediyorum."[21]

Following, he states that he waited until she broke up with him because her parents did not approve their relationship. Furthermore, he says that he can understand the parents of his ex-partner, since he believes that his life is not easy with his impairments and no parents would want a life with these difficulties for their children. In fact, this is another thing that is shared by many participants of this study, and this is associated with the internalization of the negative attributions regarding the limited functionality of their bodies and the support they need to have from others.

2.2."… because I have a dependent body"

The feelings of dependency among disabled people begin with the presence of physical limitations. Inevitably, disabled people are physically dependent on the help that they get from others in order to continue with their lives; though the degree of this dependency changes one person from another. However, as it is the case with having a different body comparing to the bodies of non-disabled others, physical dependency becomes something more than just needing physical help from

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[21] "Do you know another reason why I kept it? It was the society. The society, because you're impaired, someone normal accepted you, and your nose went up to the air. So, when you try to break up, they say, 'so, you've found the beautiful girl, she likes you with your everything, you have no right to break up because you're impaired'. No matter what that person is, I mean, they can have a lower position, but just because they are healthy makes disabled people in a lower position from the perspective of the society, I said, 'man, you don't have the right to break up, they will blame you for this'. So, I feel like I don't have the right to break up."

others, especially when it is combined with the negative attributions about dependency. To be more precise, the negative feelings regarding dependency are not necessarily associated with the actual level of physical dependency or nature of disability but with the meaning given to the state of dependency by particular individuals. For example, although Hande can actively use her upper body and therefore, evaluates her physical condition better than many other disabled people, she is very concerned about her dependency to her family to change her catheters regularly, and she perceives this process as the most limiting factor of her life. Similarly, Işıl, who is actually married now, expresses her feelings regarding her dependency on her family as follows: "*mesela ailemden çok ihtiyaç duyduğum noktada onların yardımını isterim hep. Kendi başıma ne kadar bağımsız olabilirsem o kadar kendimi iyi hissediyorum. Kendime güvenim daha fazla oluyor. Ama ne kadar bağımlı olursam, o güvenim biraz daha azalıyor, kötü hissediyorum*".[22] That is, in order to understand the negative feelings associated with dependency, it is important to understand what dependency means for each person with disability. For instance, Işıl experiences her dependent body through the experience of being a burden, which will be discussed at the next section, whereas Ülkü feels that she doesn't have any control on her environment as a result of her physical limitations as she explains with the following words:

> "Şey, kontrol, hayatı kontrol edememe. […] İşte, mesela yatakta, yatakta kaldım, yatakta kaldım. Artık hayatımın kontrolü bende değil. Bitti yani, o kontrol edememe duygusu şey yapıyor beni geriyor. Ya da eşimle ikimiz evdeyiz, akşam yattık. Sadece ikimiziz ama. Olası bir durumda, ona bir şey olursa ben ne yapacağım ya? […] Hani, şeyi bile arayamam, ambulansı bile arayamam, mesela gibi." [23]

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[22] "For example, when I really need, I can always ask help from my family. I feel better when I can be as independent as I can on my own. My self-esteem increases. But as I become more dependent, my self esteem decreases, I feel worse."

[23] "I mean, not having control on your life […] Like, for example, I'm in bed, I will stay in bed. I have no control over my life anymore. It's over, and this feeling of not having control really puts my nerves on edge. Or like, me and my partner are home, we go to sleep – but just two of us. What will I do if something happens to him? […] I even can't call the ambulance"

In other words, one aspect of dependency is experienced in relation with the direct effects of impairments on one's life. However, besides the personal attributions, the reactions given to dependency are also influenced by the society's idealization of the ability to move independently and disabled people's internalization of this idealization. As it is discussed above (Category #1: The interaction of impairments and social barriers), disability is seen as a tragedy and presence of physical limitations necessitating the help of others is the main reason for this perception. For instance, many participants reveal that they are expected to be grateful for not having more serious disabilities, which indicates that dependency is perceived as something negative by the society. In line with this, Ömer explains how he is mistaken for a beggar because of his disability by some non-disabled people, even though his disability is not a barrier to work and make money:

> "Ama garip bakan, burun kıvıran, biraz önce dediğim gibi, dilenciymişsin gibi gören… Çok kucağıma para atıldığını bilirim ben. Kucağıma para bırakıldığını… ki ben "belediyede çalışıyorum abi, niye verdin bunu bana?" dememe rağmen. […] "Ben", dedim "eve gidiyorum. Ayrıca bunu almam, ben çalışanım, belediyede çalışıyorum" dedim. Böyle de şok oluyorlar. Parayı geri alsa bir türlü, almasa bir türlü. En nihayetinde, onlar da insan tarafları daha dengelenip şey diyor, "onun için vermedim" diyor, "git bir yerde yemek ye diye verdim" diyor."[24]

This account demonstrates how non-disabled people are inclined to see disabled people as more dependent than they actually are. Moreover, it also exemplifies the common tragedy approach to disability in Turkey, where disabled people are objects of pity, cared by non-disabled others, even by those who are not expected to care for others, such as children or elderly. In turn, this perception also affects how dependency is experienced by disabled people themselves. For instance, as a person who has a progressive disease since he was 30 years old and who has been exposed to such norms for a long time, Burak (45) describes the time when he started using a

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[24] "There are lots of people who despise you, who see you as a beggar. They put money on my lap several times even if I say I work in municipality. They are very surprised and they don't know what to do with the money they offer. Finally, with their humanity, they say, 'I didn't give it for that, I gave it for you to eat something'".

wheelchair as: "*ilk sandalyeyi kullanmaya başladığımda çok şaşırdım. İlk manüeldi, babam sürüyordu. Ben diyorum, 35 yaşındayım, babam 80 yaşında, sapasağlam. Utandım ya, utandım hocam.*"[25]. This quote demonstrates how dependency can be experienced as a weakness or as a loss of social status even by disabled people, as a result of the internalization of ableist norms. In fact, Işıl, whose accounts on dependency were provided above, also expresses her expectations from herself as follows: "*Olabildiğince az bağımlı olmak istiyorum insanlara ama tabii ki fiziksel anlamda çok bağımlıyız. Ama en azından ruhsal bağlamda, ne bileyim, fizikselin dışında daha az bağımlı olabilirim*"[26]. By saying this, Işıl emphasizes the importance of feeling independent apart from her actual dependency to others, which does not seem possible when physical dependency carries negative meanings such as weakness or lower social status compared to others.

Disabled people see their dependency as another barrier to romantic relationships and sexuality, as a result of the idealization of the ability to move independently in the society. First of all, asking help, especially from parents, becomes problematic when disabled people want to socialize with their actual or potential partners. For instance, both Hande and Ülkü clearly state that they didn't want to be given a ride by their parents when they were going to meet with their actual or potential boyfriends, which limited their frequency to see each other. In fact, Hande believes that buying an adapted car for herself has had a substantial effect on her romantic relationship:

> "Benim şimdiki sevgilimle en büyük ilerleme sebeplerimizden bir tanesi, ailesine araba satın aldırmıştı erkenden. Onun arabası olduğu için, kimseye ihtiyaç duymadan onunla çıkabilirliğimiz vardı. Onun bize çok büyük bir katkısı oldu. O arabayı satınca, nasıl olduysa, ben

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[25] "When I first started using the wheelchair, I was very surprised. First one was manual. My father used to push it. I used to say, I'm 35 years old, my father is 80, he's all healthy. I was ashamed, really ashamed.

[26] "I want to be as less dependent as I can be to other people but of course we are very dependent physically but at least, I can be less dependent psychologically, apart from my physical dependence."

> bir cesaretlendim, ben araba sürmeye başladım. Görüşmen kısıtlanırsa daha sorun oluyor."[27]

What is important to note in this quote is that although Hande is also physically dependent to her boyfriend's help, she doesn't seem to attribute negative meanings to this dependency. This explanation is associated with the second reason why dependency has a negative effect on romantic relationships and sexuality, which will be discussed in detail in the next section: some disabled people believe that their physical limitations mean burden to others. However, as Hande's accounts reveal, the negative internalizations for their dependency are weaker when non-disabled people freely choose to be with them, as a result of friendship or partnership, rather than being dependent on people who take care of them as a result of kinship. Last but not least, physical limitations themselves are seen as obstacles to romantic relationships and sexuality both by the society and by disabled people as a result of internalization. For that reason, Aslı reveals regarding her difficulties to sit for long periods of time:

> "**Aslı**: Yani, belli sonuçta ileride bir evlilik, bir aşk yaşamayacağım, yaşayamayacağım kesin olduğu için. Kendimi boş yere kandırıp saçma sapan hayallere kaptırmıyorum. O konuda kendimi kapalı tutuyorum.
> **Researcher**: Peki, bunları yaşayamayacağınız nereden belli sizce?
> **Aslı**: Yani, bariz bir şekilde yaşayamayacağımı biliyorum çünkü mümkün değil, fiziki açıdan da, duygusal açıdan da yaşayamayacağımı bildiğim için kendimi kaptırmıyorum, kendimi şey yapmıyorum.
> **Researcher**: Bunda neyin etkisi olabilir?
> **Aslı**: En basitinden dışarı rahat çıkamamam, oturamamam falan filan.[…]
> **Researcher:** Peki, başka ne gibi şeyler bunları yaşayamayacağınızı düşündürüyor size?
> **Aslı**: Birçok neden var, hatta bunları düşünmem saçma olur gibi geliyor."[28]

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[27] "One of the reasons why my relationship with my boyfriend worked is that his parents bought him a car, because he had a car we were able to go out without anyone's help. It contributed so much to our relationship. When he sold the car, somehow, I took the courage and started to drive. If your meeting is restricted, it brings more problems."

This quote demonstrates the power of ableist messages on young disabled women's expectations about romantic relationship and sexuality. As it can be seen, in consequence of internalized ableism, presence of physical limitations and lack of independence become a valid reason for rejection for a young woman in her 20's. Similarly, Hande, Işıl, and Ülkü state that the loss of sensation or strength in their bodies has limited their sexual experiences at some point in their lives. For instance, Hande describes the sexual experience with her boyfriend as something incomplete because they don't have intercourse as a result of her loss of sensation below her waist, including her genitalia, which causes her to have lower sexual desire as well. However, she also states that she feels responsible for her boyfriend and she sometimes forces herself to have sex with him. On the other hand, Işıl and Ülkü, who both have full-body muscle weakness, express their worries about having limited functionality. In fact, Ülkü explains that her inability to take certain positions during sex was a problem in her previous relationship, which ended when her boyfriend said he couldn't take the burden of the relationship anymore.

In most cases, especially when the onset of disability is at an early age, disabled people feel that they are dependent on their families and they are grateful for the help they get from their parents, since their parents know how to support their needs in the best way. However, at the same time, they and their parents get worried about the quality of the care they will get in the future when their parents will no longer be able to support them. For instance, Damla, who moved to Eskişehir to work and to live alone two years ago, explains her reasoning for this decision as follows:

> "Anne-kız yaşıyorduk biz hep. Ama hani, annelerin korkusu vardır hani, ben ölünce ne olacak? İşte, 'kızım şuna gidersin kalırsın, işte teyzende kalırsın. Olmadı, paran var, işte gidersin bakımevinde

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[28] "Aslı: I mean, it is clear that I will not get married or I will not be in love in the future, it's certain that I can't. I don't fool myself and have silly dreams. I keep myself out of this.
Researcher: How it is clear that you won't have these?
Aslı: I know clearly that I will not experience these because it is not possible, neither physically nor emotionally, I don't abandon myself to this.
Researcher: What do you think causes this?
Aslı: In the simplest term, my inability to go out comfortably, my inability to sit, and so on.
Researcher: And what else?
Aslı: There are lots of reasons. It would be funny if I thought about these."

> kalırsın’. Biz mütemadiyen bunları konuşur bir aileydik. Dedim ki, ‘ben gideceğim, yaşayacağım, sen de göreceksin ve dönüp geleceğim. Bundan sonra da bir daha böyle bir şey konuşulmayacak bizim aramızda’.”[29]

This account demonstrates the lack of sense of security about the future because of the lack of systematic arrangements regarding the living conditions of disabled people in Turkey. Under these circumstances, parents and partners become the only source of support, which limits disabled people’s freedom and opportunity to make choices about their living conditions, especially for those who have impairments that require more help from others. In fact, Burak expresses his reluctance to hire a personal assistant because it is a sign of his dependency to others. Similarly, Fatih states that since he got spinal cord injury as a result of a traffic accident one month after he got married for the second time at the age of 43, his wife has provided the support he has needed and they have never thought about hiring someone else. He explains the reason of this preference with the following words: “*onlardan çok daha iyi bildiğimi ben biliyorum ve eşim bana onu çok güzel yapıyor*”[30]. Similarly, Ülkü, who is the only participant living with a personal assistant, expresses her frustration regarding getting physical support from someone who was hired with a great difficulty but who was not good enough in providing support:

> “Kendini hasta gibi hissediyorsun ya. Onu düşündüm ben. Resmen diyorsun, ben hastayım ya. Böyle şeyin bozuluyor, ne diyeyim, moralin bozuluyor gerçekten. […]Orada şey diyorsun. Ya, hani mecburum ve galiba ben bu kadar mecbur olduğuma göre, bu kıvama, evet, ben gerçekten hastayım ya, demeye başlıyorsun.”[31]

As it can be seen from this quote, the quality of the support influences one’s perception about one’s own needs, especially when ableist norms are internalized

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[29] “We always used to live as mother and daughter. But, you know, mothers have the fear, what will happen when I die? She used to say, ‘you can go and stay there, to your aunt. At least you have money; you can stay in a nursing home’. We were a family discussing this topic all the time. And I said, ‘I’ll leave and I will survive, and you’ll see and then I will be back. After that we won’t talk about it anymore.”

[30] “I know that I know better than they do and my partner provides it to me very well.”

[31] “You feel sick. I have thought about it. Literally you say, ‘I’m sick’. You’re demoralized. You say, I need it and if I need this much something like that, yes, I must be really sick”

and finding another assistant is difficult as a result of lack of systematic arrangements in the society. Although currently, Ülkü has a better personal assistant, she doesn't feel as independent as she used to feel when her mother was supporting her. On the other hand, she is also afraid to lose the good enough support she gets from her new personal assistant, because she thinks that she might be too demanding to get support from someone outside of her family. In fact, feeling as a burden is another common feeling among disabled people, and will be described in detail in the next section.

2.3. "… because I have a burdensome body"

In Turkey, disability is seen as a burden for both disabled people and their caregivers. These ableist messages imply that the extent of the support which disabled people need to have to maintain their lives is so great that neither disabled people nor people around them could carry that burden. As a result of these negative messages and the lack of accessibility and support in the society, disabled people have to deal with many negative emotions, including guilt towards the people who provide support, especially when the difficulties that caregivers face are expressed overtly. For instance, Hakan states that: "*Zorluğunu sadece sen yaşamıyorsun, çevrendekiler de yaşıyor, bunu görmek ayrıca bir yük gibi geliyor bazen. O da var*"[32] whereas Işıl expresses her disappointment when her sister kept verbalizing the support she provided before Işıl got married:

> "Ben senin için geliyorum" ve bunu çok kullandı. Bu bende üzücü bir etki yarattı. Ben ona maddi açıdan destek olmaya çalışıyorum. İşte bunlar hoş değildi. Yani bana sanki hani, ben ablasıyım, öz ablasıyım sonuçta zoraki yardımcı oluyor gibi. Bunlar üzücü şeylerdi. "Ben senin için buradayım", ki bunu söyledi de, sadece hissettirmek falan da değil. Söyleyince yıkılıyor benim için. Her şey bitiyor yani.[33]

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[32] "It's not only you who has difficulties, people arond you have difficulties too. It's another burden to see this.

[33] "'I'm coming for you', she used this so much and it really made me sad. I was trying to support her economically. To me, she was like… I'm her sister, her full sister but she was behaving like she is compelled to help. These were sad. 'I'm staying here for you', she said it, not just she made me feel it. I fall to pieces when she says that. Everything's over."

These accounts demonstrate that disabled people feel responsible for the difficulty that emerges in other people’s lives. This responsibility is heavy especially when disabled people believe that they have no other choice than their current caregivers or that their caregivers provide physical support because they are obliged to do so as a result of the relationship between them. Therefore, these messages sometimes indicate that non-disabled people would never prefer to live with disabled people, whose needs are burdensome, leaving them with feelings of helplessness. For instance, Hande reports her mother’s words about her non-disabled boyfriend as follows: “*Benim şimdi içinde olduğum ilişkiye bile, annem en başta çok şaşırmıştı çünkü kadın diyor ki, ‘bir sürü ortada kız var, yani herkes var’. Benim hayatımın kolay olmadığını annem biliyor zaten, ‘niye bunu bir insan ister?’ diyor*”[34]. In fact, many participants express that they had romantic relationships which ended because of the burden that their disabilities imposed on their partners. They also state that they understand why their partners chose to end their relationships. For instance, following, Ömer reports the difficulties in his life with disability that make understandable if someone doesn’t want to be with him:

> “Eee… şimdi, bir üst giyinme zor. Bir banyom benim, savaş alanına döner ya da büyük tuvalet. Ondan sonra, bunu temizlemek… Hangi insan bunu yapmak ister? Bunları görüyorsunuz. Bir yere gidecek oldunuz, üst katta arkadaşınızın evi, ne olacak? […] Bütün bunlar yaşamı sekteleyen şeyler, vuran şeyler. Böyle, onları bile bile nasıl şey yapabilirsin ki?”[35]

This quote reflects how disabled people are likely to internalize the ableist perspective that their daily needs are too challenging for non-disabled people both physically and emotionally, which actually might cause disabled people to be

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[34] “My mother was really surprised about my current relationship at the beginning; she used to say ‘there are lots of girl out there, there is everyone’. She knows that my life is not easy, so she used to ask ‘why would anyone want that?’”

[35] “So, now, dressing up is a trouble. Taking bath… the bathroom turns into a war zone. Or my defecating… and cleaning it. Who would want to do this? You see this. You want to go somewhere, your friend lives upstars. What is going to happen? These restrict your life. How can you… when you know all of these?”

alienated from their own bodies and needs. As a result, they stop questioning the social circumstances that worsen the experience of disability and begin to perceive their bodies as the source of the problem. For instance, Ülkü expresses her sorrow and disappointment after her ex-boyfriend broke up with her as follows:

> "Bu sekiz senelik ilişkim sandalye yüzünden bitti aslında. Yani ve şey değil, fantezi değil, konuştuğumuz bir şeydi bu çünkü. Çünkü ailesi sıkıntı yarattı açıkçası falan filan. Sonra kendisi şey yapmaya başladı, sekiz sene sonra uyandı meseleye, sıkıntı yapmaya başladı falan – ki ciddi travmaydı o bende yani. Bildiğin şey vardı, iki sene ölü gibi falan yaşadım hatta ondan sonrasında. 'Yapamayacağım', dedi. Yani,' kaldıramıyorum' dedi, 'yapamayacağım ve kaldıramıyorum. Bu kadar, işte seni seviyorum ama kaldıramıyorum çünkü zor bir şey'. Tabii ki zor bir şey. Kabul ediyorum yani."[36]

It is worth to note in each of these accounts, whether provided here or not, that non-disabled partners take a caregiver role within their relationship whereas disabled people see themselves as the passive recipients of the help, which is actually the main reason of their feeling as a burden. As a result, for those who currently have a relationship, the commitment of their partners to the relationship is something surprising and all of them express their feelings of gratitude for their partners. For instance, Fatih states:

> "Beni giydirmesi bile çok kolay bir şey değil. İşte öyle. Bunu sevgiyle yapması, çünkü çok kötü bir örnek vereceğim belki, çocuğunuz olsa üç yaşına kadar, üç yaşında sonra çiş yapmaya devam etse, vurursunuz poposuna, dersiniz ki 'lan yeter artık, eşek kadar oldun, hala mı ben senin donunu yıkayacağım, şeyini yıkayacağım?'. Ama şu anda 21 sene bitti, 21 senedir buna katlanıyor. Onun için ben "yeri cennet direkt" diyorum."[37]

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[36] "My eight-year relationship ended because of my wheelchair, actually. And it's not just a fantasy, we've talked about it. Because his parents didn't approve. Then he started doing the same, he realized the issue after eight years. It was really traumatic for me. I was like a dead person for two years after that. He said 'I can't do it, I can't stand it. That's all. I love you but I can't stand it because it's difficult". Of course it's difficult. I accept that."

[37] "It's not very easy to dress me up. She's doing it with love. I will give you a bad example but, if you had a child who kept wetting themselves until three years old, you would pat on their back and say 'Enough already! Do I have to keep washing your underwear?'. But 21 years are over now and she has stood to me since 21 years. That's why I think she deserves of heaven."

As it can be seen from this quote, partners who prefer to stay in their lives, despite disabled people believe that their needs are very demanding, are seen as the heroes and heroines of the relationship. In fact, this also demonstrates how they position themselves to a lower level within their romantic relationships as a result of internalization of negative messages regarding their disabilities. In the end, negative assumptions about the changes in the appearance and functionality of the bodies of disabled people and internalization of these assumptions regarding bodies with impairments result in the exclusion of people with disabilities from the society, and their differences from normality are blamed for that.

3. Category #3: Longing for Normality

As it is presented above, disabled people face a variety of problems in their lives, ranging from inaccessible environments to being excluded from work environments, losing their social status in the society, or facing rejections in romantic relationships and sexuality, all of which poses a threat to the psychological well-being of disabled people. In addition, being consistently exposed to idealist and ableist messages from the society increases the likelihood of disabled people's internalization of these messages. Along with the helplessness regarding the lack of accessibility and social arrangements to ensure the inclusion of disabled people in the society, these internalizations strengthen the society's conception that the problem is in the appearance and functionality of disabled people and lead disabled people to long for normality to be included to the society.

The longing for normality might cause disabled people to distance themselves from their reality for the sake of feeling and being perceived like "normal" people, which removes disability-related problems from the focus of attention. Moreover, this might even be considered as an achievement for some disabled people. For instance, Damla states:

> "Bir gün özel sektörde çalışırken, izinliyim, engelliler günü, arkadaşımı aradım. Ben bugün izinliyim dedim. Niye dedi. Engelliler günü bugün dedim. Nasıl yani dedi. Dedim engelliler günü ya, ben bugün izinliyim, hadi bir şeyler yapalım. Ya sen salak mısın dedi ya,

> sen bu izni niye kullanıyorsun ki, ne gerek var? Nasıl mutlu olmuştum böyle. Ya da bir gün şey dedim, ya benim hastalığımdan bir arkadaş var, onun yanına gideceğim. Senin hastalığın ne dediler, kimse benim hastalığımı bilmiyor ya da biz bunları oturup konuşmuyoruz."[38]

This kind of attitude towards their own disabilities has a protective role for many disabled people. First, Damla further explains that she doesn't feel the need to talk about her disability-related problems. Moreover, both Damla and Ülkü remark that distancing themselves from their reality is functional to maintain their inclusion into the society. For instance, Ülkü says:

> "Mesela gece eğlenceye mi gideceğim, kimsenin arabası falan yok, yani bizim durumlar daha kompleksti açıkçası. Yani, illa ki ben de götürülüyorum mesela ve ağır akülü sandalyeyle, SGK o zaman şeydi, bardı, SGK'nın en tepesine falan çıkıyoruz. Yani, şey bir durum, orada görmüyorsun işte, hani onlar da görmüyorlar zaten ama, daha yeni, aa evet, olabilir. Hatta şimdi ben söylemeye başladım insanlara, ben gelmeyeyim ya, şey olur. Onlar şey yapıyorlar, saçmalama falan. Ya zor olur ya, falan, yani şu an düşünüyorum."[39]

On the other hand, disabled people might feel the same longing for normality even if they don't actively try to feel like non-disabled people. In fact, the question of "What if I wasn't disabled?" in an ableist society, where ableism is more likely to be internalized, is an eliciting factor for these feelings, because disabled people believe that being free from disabling barriers, either external or internal, would mean having more chance to do more things. For instance, Aslı emphasizes the effects of physical barriers on her life with disability as follows:

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[38] "While I was working in private sector, it was the Day of Persons with Disabilities and I was on leave and I called my friend. I told them that I was on leave and they asked why. I told that it was the Day of Persons with Disabilities and we should go out. And they said 'Are you crazy? Why do you use that leave? Why do you need it?'. I was so happy to hear that. Or another day, I told,' I have a friend who has the same condition as mine, I will meet them' and they asked what is your condition? No one knows what my condition is or we don't sit and talk about these."

[39] "Like, for example, I was going out at night, no one had cars, and things were more complicated. But they would take me in any case and with a heavy electric wheelchair, they would carry me to the upstairs of the building. So, you don't see it [your disability], they don't see it either. I have just started to see it, to say people things like 'I shouldn't come'. They say 'don't be silly'… But I think it's difficult for them, I have just started to think about it."

> “Herhalde böyle bir durum olmasa daha çok dışarıda görüşürdük. Şu anda daha çok evin içinde görüşüyorum. […] Dediğim gibi, sadece gittiğim yerler, gidebileceğimiz yerler, mesela sinemaya çok nadir gidiyoruz arkadaşlarımla. Belki her hafta sinemaya gitmek değil de, işte, yılda bir sinemaya gitmek gibi oluyor. Sadece o yönde kısıtlıyor beni. Daha çok evin içinde, yakın, evin önündeki parkta falan oturuyoruz en fazla. Bir kafeye gidelim, şuraya gidelim buraya gidelim sıkıntı oluyor bazen.” [40]

Similarly, Fatih explains how he thinks his life would be if he wasn’t disabled and he wasn’t excluded from his work environment as follows: “*Ben mutlaka cemiyetlerde bir noktalara gelmeye çalışırdım. Cemiyetlerde, derneklerde… Hoş, derneklerde geldim de… Mesela, bir şeyim meclise girebilmek, girmek olabilirdi. Partiye girer, çalışır, çünkü kolay kaynaşan ve şey bir insanım. Yani, onu becerebilirdim, yani içime öyle geliyor”.*[41] Therefore, beyond the physical and social barriers, this quote emphasizes the role of internalized ableism on the lives of disabled people, which prevent them to reach to their own potential. Besides, longing for normality is more intense when disabled people start perceiving the differences in their body appearance and functionality as the core of the problem. This perception is especially more common in the face of exclusion from relationships. For instance, Ömer states about her partner who broke up because she didn’t want to be seen with him in the public anymore:

> “…o kitabı okuduğumda özrümden nefret ettim mesela. Çünkü [doğal] seleksiyon benim yok olduğumu söylüyor. Sinir oldum, niye özürlüyüm yani? Niye yok olmaya mahkûmum? Ya da kız arkadaşımla olan durum. Bir adım geriye gidiyorum. Özürlü olmasaydım, inan, paçama yapışır yerde sürüklenirdi benim için. Ben inanıyorum, öyle olurdu, özürlü olmasaydım. Ben ‘gidiyorum, terk ediyorum’ deme noktasında olup o paçalarıma, ayaklarıma yapışır Kızılay’da sürüklenirdi. Belki de özürlü olmasaydım, o

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[40] “We would meet outside if this condition didn’t exist. Currently, I see them at home. […] As I said, only the places I would go, or we would go… For example, I go to the movies very rarely with my friends. So, not once a week, but like once a year. It restricts my life only in this way. We see each other at home usually, or at park near our home. It’s difficult to go to a cafe, to other places.”

[41] “I would try to advance in some societies or associations. I could do that in associations but… I would try to become a member of the parliament. I would support a political party, I would work because I’m a sociable person. I could do that, I feel like this.”

> arkadaşımla karşılaşmayacağım gibi, belki de ben bir mankenle beraberdim"[42]

In fact, this quote demonstrates the extent to which disabled people might believe that disability has a negative effect on their lives. Therefore, according to disabled people who have higher levels of longing for normality, the solution to the problems in their lives is through getting rid of their disabilities. This is why, possible treatments are awaited with expectations and hopes. For instance, Burak states: "*Ben işte isterim tek sağlık, sapasağlam. […] 2017 yılına bulunacak diyorlar, ama belki 10 yıldır, "seneye bulunacak", "seneye bitti" ama hala bir şey yok.*"[43]. Similarly, Hande explains that she makes great effort to preserve her strength in her legs and to not leave her walking again to chance in case that she recovers from spinal cord injury one day. However, she also expresses that she feels helpless when she can't get what she wants in return:

> "Fizik tedavilerde, bir hareketim, bir şeyim var mesela, seviniyoruz ama bunu artışını görmüyorum ve çabalarken zorlandığımı görmek, çabaladığım halde bir gelişme görememek çok negatif etkiliyor. Bir de suçlu hissim oluyor, […] diyorum ki, acaba gelişmelerin olmayışının sebebi, ben yetersiz mi çabalıyorum? […] Belki daha fazla uğraşabilirim ama belki de bu yeterlidir. Belki de sebep bu değildir. [Yapmak] istemiyorum ama onun suçluluğu geliyor, gerçek sebep o mu hiç bilmiyorum. Net olarak "şunu yaparsan olacak" diyen yok. Bunlar da haliyle negatif etki yapıyor."[44]

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[42] "When I read that book, I hated my impairment because [natural] selection says I will be eliminated. I was annoyed, why am I impaired? Why am I doomed to be eliminated? Or the thing with my girlfriend. I take a step back, if I wasn't impaired, believe me, she would never leave me, she would grovel on the ground for me if I could have said 'I'm leaving you'. If I wasn't impaired maybe I wouldn't have a relationship with her, instead I would be with a model."

[43] "I just want health, want to be in perfect health. […] They've said the cure would be found until 2017, they've kept saying 'it will be found next year' but there's nothing yet."

[44] "During my physiotherapy, I can make a move and we get happy but I don't see any further move and seeing that I have difficulty doing it, having no improvements even if I make efforts influences me very negatively. I feel guilty. […] I say, maybe the reason why I don't make any progress is that I don't try hard enough. […] Maybe I can try harder but maybe it's enough. Maybe this is not the reason. I don't want [to do] it but I feel guilty for that. I don't know if this is the real reason. There is no one clearly saying 'if you do this, it will happen'. So, all of these influence me negatively."

It is important to note that looking for a cure or exercising in order to improve their physical conditions and to recover is expected. However, as it can be seen from the quotes above, believing that becoming or turning back to normal is the main solution to the problems that are associated with having disability complicates the experience of disability. The difference between these two reactions lies at the emphasis on normality in the latter. Moreover, as disabled people focus more on changing themselves and less on removing physical and attitudinal barriers in the society, which are actually the main reasons of internalization and longing for normality, they are less likely to advocate for their own rights. In fact, Hande expresses this situation with the following words after she emphasizes the state's responsibilities for disadvantaged groups: "*Aynı şekilde engelli bireyleri bu şekilde görünce, birinin bunu kırması lazım, bu şeyi yıkması lazım gibi geliyor. Tabii hiçbir şey yapılamıyor. Benim de yaptığım hiçbir şey yok. Bir gün iyileşirsem uğraşır mıyım bu konuda, onu bile bilmiyorum, kaçarım gibi geliyor*."[45] As a result, the ableist system remains unchallenged or gets even stronger, as it forms a vicious cycle with the existing social barriers and internalization of norms.

Until now, the elements of the vicious disabling cycle, namely social barriers, internalization of norms, and longing for normality, were presented. It is important to note that not everyone gets stuck in this cycle or not every aspect of the lives of disabled people is in the cycle. Therefore, the following sections will include the process and the results of breaking this ableist cycle on the grounds of the participants' accounts, specifically becoming a separate individual through questioning the idealist and ableist norms in the society, accepting the authenticity of the experience of disability, and starting to defend one's own rights.

4. Category #4: Becoming a Separate Individual

Disabled people describe some experiences by which they can start questioning and challenging the norms of the society. These experiences also help them to review

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[45] "Similarly, when I see disabled people like this, I feel like someone has to break this, someone has to destroy this. Of course, nothing can be done. I don't do anything either. I don't know whether I would do anything if I get well one day."

and revise their internalizations of ableist norms. As they move further away from their previous internalizations, they get closer to becoming a separate individual, being able to live independently and confidently. Here, being able to live independently does not indicate to be all self-sufficient without any help from others but refers to be able to make choices regarding one's own life equally as non-disabled others. These decisions include important life decisions like deciding where to live, with whom to live, and how to live as well as small decisions like how to spend one's weekend. Therefore, becoming a separate individual is an important step to become an adult in a society where disabled people are frequently infantilized, as presented above.

As described above, the first element of the ableist cycle is the presence of social barriers, either in a physical or attitudinal form. Thus, one way to break this cycle is to remove these barriers in accordance with the needs of disabled people. For instance, Hakan explains how arranging an adapted car within his university that is responsible for transporting disabled students to their home or to their classes has enabled him to feel less dependent on his parents' help:

> "Her gün beni annem-babam götürsün yerine, birimde böyle bir hizmet olsun, bu birilerinin işi olsun, ben ve benim gibi insanların ulaşımına yardımcı olsun. Bu da o yükü başkalarından almak içindi. Bu, birilerinin işi olduğunda, hem onun görev duygusunu besler hem de bizim bağımsızlık ve motivasyonumuzu arttıran şeyler. Sisteme oturması en iyisi, ulaşmamız gereken en ideali zaten. Biz de galiba bu şekilde bir yön kazanıyoruz. Artık bunun bir üst tarafı, toplumun, sistemin, iş yerlerinin ve herkesin böyle olması."[46]

Similarly, Damla states that when she started to live alone in a different city apart from her mother, she realized that she was no longer disabled by the environment:

> "Eskişehir'e gittiğimde şey dedim, evet, sakat olabilirim, özürlü olabilirim ama ben engelli değilim. Ben artık engellenmiyorum.

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[46] "Instead of my parents carrying me every day, there is a service at the university, some people can be employed and they help me and other people like me to transport. It was to remove the burden from others' shoulders. When this is a job for some people, it increases their sense of responsibility and our independency and motivation. Systematic arrangements are the best that we should reach. I believe we find our direction by this way. The next step is the arrangement of the society, system, workplaces, and everyone like this."

> Fiziksel olarak da, aile olarak da, çevre olarak da, hiçbir şekilde engellenmiyorum ve ben normal bir birey gibi, evinden işine işinden evine giden asosyal bir insan modunda yaşıyorum."[47]

These accounts indicate that disabled people can feel "normal" or like non-disabled others without having to become non-disabled as long as the society is arranged according to their needs. This way of thinking and, therefore, demanding one's rights are only possible if disabled people can realize that the norms in the society regarding the appearance and functionality of their bodies are ableist in nature and do not reflect the reality of disabled people. However, this realization is not always easy for everyone and requires some changes in personal and relational characteristics.

First of all, disabled people who can separate themselves from others, especially from their parents, are the ones who can manage to decrease their unnecessary dependency to others. For some disabled people, this is achieved by the use of assistive devices, such as manual wheelchairs, electric wheelchairs and/or adapted cars, or by the use of assisting personnel, by challenging their internalization of negative evaluations regarding the use of these devices. For instance, Işıl explains that although she first thought that she became more dependent when she started to use an electric wheelchair as a result of her beliefs regarding wheelchair users, she realized that it has provided her freedom since the beginning:

> "Akülü de özgürlük işte, onu söyleyeyim. Şimdi dışarıda ben akülümle içine girebildiğim her binada ben işimi görebilirim. Hastaneye gidiyorum, ilacımı yazdırıyorum, muayene oluyorum. Faturamı yatırıyorum, alışverişimi yapıyorum. Bunları diğer insanlar yürüyerek yapıyor, ben böyle yapıyorum ama yapıyorum. O da bir özgürlük. Akülü de özgürleştirdi diyebilirim."[48]

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[47] "When I moved to Eskişehir, I said 'Yes, I can have impairments, I can be impaired, but I'm not disabled'. I am not disabled anymore. Not physically, not by my family, not environmentally. I am not disabled in any way and I live like a normal individual, like an asocial person going from work to home."

[48] "Electric wheelchair is a freedom, I can say. I can do anything in any building I can get into with my electric wheelchair. I go to hospital, I can have my prescription, I get examined. I pay my bills, I do my shopping. Other people do all of these by walking, I'm doing it that way. It's a freedom. I can say that my electric wheelchair gave me freedom."

This quote reveals that with the help of her electric wheelchair, she feels more independent and more like non-disabled people than trying to walk with the help of others, contrary to society's and her expectations. Similarly, Ülkü states that getting an electric wheelchair enabled her to feel more confident about herself, which helped her to have stronger friendships and romantic relationships. Besides, she also expresses her feelings regarding her becoming more independent from others as follows: *"...şunu gördüm aslında, kimseyle, evet, yakın arkadaş olabiliriz ama yan yana olmak zorunda değiliz. [...] Hani evet yakınız ama dip dibe de olmak zorunda değildik bir taraftan. O yüzden kendimi iyi hissettim aslında.*"[49]. These words emphasizes the importance of individuation for disabled people, as non-disabled others, to improve their self-esteem.

Secondly, having positive experiences with the help of supportive families and friendships has a crucial effect on questioning the ableist norms in the society. Still, it is important to note the differences between the times when they are really supportive by encouraging psychological growth of disabled people and when they are disabling by perpetuating the norms about appearance and functionality of disabled people's bodies, taking a role of the society as the smallest unit of it. Some examples of disabling attitudes of the families were presented in previous categories. Besides that, overinvolvement is one of the factors that prevents disabled people to become a separate individual from the society, while seemingly supporting them. For instance, Damla explains how her mother keeps being involved with her even after she has lived on her own for two years:

> "**Damla**: Sürekli bir güç var, seni koruyan, kollayan. Mesela yatağa yatarken mutlaka beni uyarır, sandalyeni kilitledin mi? Sandalyene geçerken dikkat et. Banyoya bensiz girme, şunu bensiz yapma. Ama baktığında sadece hafta sonunda bunları annemle yapıyorum. Geriye kalan beş gününü ben bu şekilde yaşadığım hayatı ben anneme anlatamıyorum. Anne, rahat bırak. Anne, sen olmasan da bu iş dönüyor. Hani, bir huzurlu olalım gibi. […]
> **Researcher**: Evet, peki bu size kendinizle ilgili ne hissettiriyor olabilir?

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[49] "…I saw that we can be friends but we don't need to be side by side […] Yes, we are close but we don't need to be cheek to jowl. That's why, I felt good".

> **Damla**:Yani, köşeye sıkışmış gibi, hani, böyle, ona bağımlıymışım gibi hissettiriyor açıkçası. Bağımlı olmadığımı kanıtlamak için kalkıp Eskişehir'e gitmiş olmama rağmen, geriye dönüp baktığımda, her şeyi baştan yaşayacakmışız hissi veriyor bana bu. Hiçbir şeyin çözülmediğini düşünüyorum."[50]

As it can be seen from this quote, overprotective or overinvolved attitudes from parents might lead to the feelings of dependency even when disabled people can manage to live independently. This effect is even stronger for disabled people who continue to live with their families, as they don't have any experience of independent living. Therefore, questioning and challenging the ableist norms in the society and becoming a separate individual become a harder task for them.

Third, experiences gained with people from outside of the family become crucial for becoming a separate individual. For instance, Damla further explains how one of her friends played a significant role in achieving her independence when she used to live with her mother as follows: "*Annemin hiç sevmediği bir arkadaşım vardı beni ilk sokağa çıkaran arkadaşım. Bütün çılgınlıkları onunla yaptığım, içtiğim, sarhoş olduğum, parklara kafelere gittiğim tek arkadaşımdı o benim. […] Sağ olsun, bana dışarı çıkmayı öğretti. Hani, adım atmayı öğretti*."[51]. In other words, she describes her mother's difficulty to allow her to differentiate herself from her mother and to be independent. In fact, as a result of the combination of disabling physical environment and psychological unpreparedness of families to allow their children to be independent, disabled people in Turkey are commonly exposed overprotective attitudes from their parents. However, forming friendships which supports their needs of separation and individuation, disabled people can have different

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[50] "Damla: There is always a power that protects you. For example, when I lie to the bed, she keeps warning me, 'did you lock your wheelchair? Be careful when you move to your wheelchair. Don't take a bath without me. Don't do that without me'. But when you look, I do these with my mother only at the weekends. I can't explain to her that I spend other five days like this. 'Mom, leave me alone, this works without you, let's be in peace'.
Researcher: And how does it make you feel about yourself?
Damla: Like, I'm stuck, like I'm dependent on her. I moved to Eskişehir to prove her that I'm not dependent but I feel like we will do everything all over again. I think nothing is solved."

[51] "I have had a friend that my mother didn't use to love at all, the one who first took me out. I did all craziness with them. My only friend that I took alcohol, I got drunk, I went to parks, cafes with […]. They taught me to go out. They thought me to take steps."

experiences which are helpful for them to question and challenge their internalized ableism. For instance, Ülkü notes that having friends who don't see her disability as a barrier to anything has enabled to do things that her non-disabled friends take for granted, such as going to bars, staying overnight at her friends' houses, taking trips to other cities and so on. Moreover, for some disabled people, forming friendships with other disabled people is empowering as well. For instance, Işıl shares the positive effects of her friends with disabilities, which she met in an online platform, on changing her perspective towards her own disability:

> "Mesela yine görme engelli bir arkadaşım var, o kadar kendini geliştirmiş bir çocuk ki, bana yön tarif ediyordu. Yani Ankara'da nereye nasıl giderim, o bana tarif ediyor ve hiç görmüyor. Dalış yapıyor, spor yapıyor, tatile gidiyor. Yurt dışına çıkıyorlar. Ben bunları gördükçe neler aşılabilirmiş, neler yapılabilirmiş diye de görüyorum. Yani, hayatımda şansım şu oldu, iyi engelliler gördüm. Güçlü. Bir şeyleri başarmaya çalışan. Onlar bana bayağı bir şey kattı ya. Mücadele etme ruhunu onlar veriyor."[52]

These explanations indicate that questioning of ableist norms and challenging one's own internalizations enable disabled people to have wider opportunities, especially when their environment is physically arranged according to the needs of disabled people. In fact, Işıl further explains that seeing her friends with neuromuscular diseases getting married helped her to see that it was also possible for her and that she could find ways to be more independent if she needs one day, such as buying a patient lift or hiring an assistant. Therefore, she emphasizes that her friends with disabilities provide a variety of solution to her everyday problems, including issues regarding her independence in her marriage.

The internalizations of the norms regarding the appearance and functionality of the body are questioned more easily by the participants who are or were married, since they believe that their partners are not or were not with them out of obligation.

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[52] "For example, I have a blind friend, he improved himself so much that, he used to give me directions. Like, how should I go from one place to another in Ankara, he explains it to me and he doesn't see at all. He dives, he does sports, he goes to vacations. They go abroad. I understand what can be done seeing all these things. I was lucky to meet with strong disabled people, who strive to be successful. They contributed a lot to me, they give me the spirit to fight."

Therefore, their partners who can maintain a different attitude from the society towards their disabilities play an important role in challenging the ableist norms and internalized ableism. For instance, Işıl further explains this process as follows:

> "…eş olmak farklı bir şeymiş. Aile, kardeşler farklı bir şeymiş. Ben onu anlamış oldum. O yüzden evlendikten sonra artık çok korkutucu olmayabilirmiş evlilik. Senin yanında, sana destek olan bir insan var, seni bu şekilde kabul eden, birbirinize açık olabildiğiniz, çok korkutucu değil. Öyle söyleyeyim. Ama içine girmeyince ailen senin için çok şey yapıyor, sen evlenme şöyle olur böyle olur. Herkesin kafasında bir şey var. Toplum baskısı ve aile baskısının dışına çıkmak gerekiyormuş. Gerçekten. Senin kalbin ve aklın ne diyorsa onu biraz dinlemek lazım."[53]

As a result, disabled people are more likely to defend their right to choose where to live, with whom to live and how to live, without thinking that they cannot have an independent life. In other words, separation from their families becomes easier when they realize that another way of living is possible. For instance, Doğan, who has been living alone since he was divorced 6 years ago, describes his current life as follows:

> "Buradaki evde bulaşıklarımı kendim yıkarım, yemeğimi kendim yaparım. Annemler şimdi burada, onlar yapıyorlar, rahat bir buçuk aydır ama gidecekler sonra iş başa düşecek. Yaparım, çok güzel de yemekler yaparım. […] Şimdi benim huzurum var. Kendim, özgürüm. Akşam çıkıyorum, istediğimi misafir ediyorum, istediğimi ağırlıyorum. Bizim hayatımız var, devam ediyor. Cinsel hayatımız da var. Oluyor, seçiciyim ya.".[54]

As it can be seen, with these words, he explains the possibility to maintain one's life contrary to society's expectation from disabled people. Besides, he also emphasizes that being independent does not necessarily mean being self-sufficient in every task

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[53] "…being a partner is different than family and siblings, as I understood. That's why marriage is not scary anymore. There is a person who support you and accept you as you are. You can be open to each other. It's not scary. But before marriage, your family says things like 'don't get married, this can happen, that can happen'. Everyone thinks something. You should move away from society's and your family's oppression. Really. You should listen what your heart and mind says"

[54] "Here, I wash my dishes by myself. My parents are here now, they do it and it's been easy for months but they will leave and then I will do everything. I can do, I can cook very well. […]. I have peace now, I'm free. I go out at nights, have guests. I have a life, it goes on. I have a sexual life too. I'm picky."

of daily life. Instead, disabled people who can manage to become a separate individual as non-disabled people are the ones who can use the provided support to grow stronger and who can accept the challenges of separation and individuation in order to reach to their authentic self, in which they are able to adjust to the ways of meeting their needs, without limiting themselves with internalized ableist norms. Moreover, for some people, challenging internalized ableism also increases the likelihood of taking part in disability activism to ensure that all disabled people can fully enjoy their fundamental rights and freedoms.

5. Category #5: Authenticity

Following the questioning and challenging their internalized ableism and becoming a separate individual, disabled people start to see their disability as a part of various ways of being, rather than a deficiency. This changes the meaning that they attribute to the differences in the appearance and functionality of their bodies. As for the appearance, for some disabled people, having a body with impairments is not a reason for rejection anymore. Instead they embrace their own appearance and believe that they are sexy and attractive as they look. For instance, Işıl expresses how her self-consciousness about her disability has changed over time as follows:

> "O zamanlar şu da var. Hastalığının bunlar daha ilk zamanları. Daha oturma zamanları. O zaman insanların bakışı rahatsız ediyor. Şu anda da bakıyorlar, sonuçta ben akülüyle gidiyorum. İlla ki bakıyorlar. Çoğu dönüp dönüp bakıyor ama şimdi ona gülerek karşılık verebiliyorsun. Hani, sen kendin kabullendiğin için o insanların bakışı daha az rahatsız ediyor […], tabii ki hoş bir şey değil ama o kadar rahatsız oluyor muyum, hayır."[55]

This quote indicates disabled people's belief that they have a strange body lose its strength when they are able to evaluate themselves independently from the society. Similarly, Ülkü states that she has always thought that she looks sexy and beautiful. On the other hand, Damla explains that she used to be more worried about her

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[55] "It was the first times of my disease, the adaptation times. I used to be bothered by others' look. They stil keep looking, because I use an electric wheelchair. They look certainly, but you can laugh at it. Because you can accept yourself, you're less bothered. […] It's not nice but am I bothered that much? No."

appearance when she was an adolescent because she was comparing herself with the beauty standards in the society, although she doesn't do so anymore. In line with this, male participants express less dissatisfaction with the differences in their appearances. Rather, they evaluate themselves as a whole. For instance, Ömer states:

> "Doğal olarak ben burnumu "amaaan, burnum çok büyük" diyip onu özel olarak almam ki. Bileğim yamuk diye… ama ben bir bütün halinde, o yamukluklarla, o burnumla, o ayakla… Yok işte, incelemiyorum. İncelemiyorum. Ayak parmağım, kemiğim deforme olmuş mesela, ama o tutup da parmağı açarken acıtmanın dışında, bana ne, öyleyse öyle. O öyle. Algılamıyorum bile. Duvara dayadığında, ayakta duruyorsam, dizler bükülmüş, kollar kasılmış, suratta şekil şemal gitmiş, ama bana ne yani."[56]

This quote shows how he manages not to internalize the negative looks by non-disabled people towards his body with a different appearance. Similarly, Hakan believes in the importance of paying attention to one's appearance rather than physically conforming to the expectations of the society. As it can be seen in the following quote, this kind of appraisal enables him to be hopeful about romantic relationships and sexuality: "'*Engelli oldum ve artık kimse benimle birlikte olmak istemez, hayatına almak istemez' gibi bir düşünce bana saçma geliyor. Seni gören, tanıyan insanlar hayatına dâhil olmak isteyebilir ve her zaman kapımız açık bunlara.*"[57]. Therefore, not internalizing the norms regarding their appearance is associated with better adaptation of disabled people to their own reality.

As for the functionality of their bodies, questioning and challenging the norms regarding the dependency and burden of disabled people results in the acceptance of their physical realities, as well as their individual needs and their individual roles

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[56] "So, I don't evaluate my nose separately, saying 'oh, it's too big' or because my ankle is skewed. I'm a whole with everything I have, these skewnesses, this nose, this foot… I don't investicate. I don't care if my toe is deformed, except that it hurts when you try to open it. That's the way it is. I even don't perceive. When I stand by the wall, if I can stand on my legs, I don't care if my knees are bended, my arms are contracted, my face is deformed, I don't care"

[57] "It doesn't make any sense to think 'I became disabled and no one will want a relationship with me, no one will want to have me in their lives'. People who know you might want this and I'm always open to them."

within their relationships. The acceptance of their physical realities is first achieved through the acceptance of their medical condition – or impairment. Acceptance of the impairment is a different process for each individual, affected by various internal and external factors as summarized above. Besides those, religion is another factor that helps some disabled people to accept their physical realities. For instance, Doğan explains how he has arranged his life after accepting his disability:

> "Engelliyim tamam kabullenmişim, eyvallah, Allah'tan gelmiş, yapacak bir şey yok, kader kısmet, ona da eyvallah diyorum. Tamam. Artık bu hayatı yaşıyoruz, düzelme durumu da yok. Bu hayat benim hayatım. Bu hayatı nasıl yaşanır hale getirebilirim, yani istesem kendi hayatımı zehir edebilirim. Ben şu anda kendi hayatımı kolaylaştırmak için çalışıyorum."[58]

He further explains that he can do anything that non-disabled people can do, such as doing housework, going out, going to vacations, and driving car, with only one difference that he does all of these things in his wheelchair. Therefore, once the acceptance is achieved, disabled people start having less conflict with themselves and their disabilities. For instance, Damla states:

> "Eskişehir'de yine çok mutlu olduğum bir gün öğle arasında eve gidiyorum. Yaşlı amcalara teyzelere gülmeye, gülümsemeye çalışırım hep. Bir amcaya gülümsedim, 'yavrum' dedi, 'ben sana çok üzülüyorum. Böyle, gencecik yaşında, güzelsin de dedi, geliyorsun, gidiyorsun' dedi. Dedim, 'bana niye üzülüyorsun, sen kendine üzül, benim işim var gücüm var, gidiyorum geliyorum, ailem var, sevdiklerim var. Sen' dedim 'kendine, kendi yapamadıklarına üzül, bana niye üzülüyorsun?' Adam hiçbir şey demedi, diyemedi. Sonra dedim ki, kendime üzülmeyeceğim, kızmayacağım. Ben iyi bir konumdayım, insanlara bunu öyle ya da böyle göstermek zorunda da değilim. Ben yoluma gideceğim, bakacağım"[59]

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[58] "I'm disabled, OK, I accept that. It's fate, there is nothing else to do. OK. I live this life from now on, there is no way that it gets better. It's my life. I am working on how I can make this life more liveable. I can make my life miserable but I'm trying to make my life easier for myself."

[59] "I was in Eskişehir and going back to home from work in a happy afternoon. I always try to smile to old people. I smiled to an old man and 'my little one' he said, 'I feel really sorry for you… you're young and beautiful, you're coming and going like this'. I said 'why do you feel sorry for me? Feel sorry for yourself. I have a job, I can come and go, I have a family, I have friends, I have the loved ones. You should feel sorry for yourself, for the things you couldn't do, why do you feel sorry for me?'. Then I said to myself: 'I will not feel sorry for myself. I will not be angry. I'm in a good

This quote indicates that once disabled people can find ways to spend their lives as non-disabled others, which was possible for Damla through the accessibility of the city in which she lives, their need to change their own bodies to be included in the community decreases. Therefore, they can accept themselves as they are because they don't have negative internalizations about their limited functionality.

Secondly, as disabled people accept their physical realities, they are more likely to be able to find solutions to their problems that will increase their independency. For instance, Hande explains why she didn't want to use an adapted car for a long time as follows:

> "Üniversiteyi kazandığımda bir ödül törenine gitmiştik. Orada bir adam dedi ki bize 'Tebrikler, ne güzel' falan, 'Muhakkak kızınıza bir araba alın' dedi. Biz de dedik ki, 'Yaa istemiyoruz biz, ben iyileşeceğim zaten, ne gerek var böyle şeylere?' falan. Çünkü ben iyileşeceğim zaten, ne gerek var? Hep bu mantıkla gittik. İşte üstünden yıllar geçti. Bölümden bir arkadaşım demişti ki, "sen araba alsana", kıza dedim ki "ben inşallah iyileşeceğim, istemiyorum araba almayı". […] "Niye bana bunu yakıştırıyorlar?" isyanı geliyordu o sırada."[60]

However, as explained in previous categories, having an adapted car has given her the freedom to meet with her partner as she wishes. Similarly, Işıl explains that she has accepted her impairment when it started to get worse and now she can see that one day, she might need to buy a patient lift or hire a personal assistant to decrease her feelings of being a burden to her partner. Therefore, these accounts reveal that the acceptance of individual needs, without internalizing the negative evaluations regarding disabilities and assistive devices, such as wheelchairs, patient lifts and adapted cars, and other options such as personal assistants, helps disabled people to become more independent and to be more included into the society.

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position and I don't have to show it to other people in one way or another. I will just keep going my way."

[60] "When I first got into university, I attended to an award ceremony. There, a man said to us 'Congratulations, how nice, and you should certainly buy a car for your daughter'. We said to him: 'We don't want a car, I will get well, who needs it?' Because I will get well, why bother? We always had this mentality. Years after, a friend from the department said: 'You should buy a car'. I told to her: 'Hopefully I will get well, I don't want to buy a car'. […] I was getting angry to them like 'Why they think I deserve it?'"

Lastly, as one's conceptualization regarding their own disability changes, they can evaluate their relationship with others from a different perspective. By this way, they realize that some people can freely choose to be with them regardless of their dependencies and as a result of these positive experiences, disabled people start to feel less like a burden. Therefore, their limited functionality becomes less problematic and they can use this help to become a separate individual and to accept their authenticity. In other words, their physical dependency to other people becomes acceptable because this is not associated with having a lower status within the relationship in their conceptualizations anymore. For instance, Ülkü expresses her relief when she realized that she can do whatever they want with her partner:

> "Eşim de annemin yöntemini öğrenmek için çok çaba harcadı. Tuvalete girme vesaire, liftsiz ne yapabiliriz? Bara gittik, nasıl girebiliriz tuvalete, çok daracık yerlerde ne yaparız falan? Hatta biz şöyle bir çılgınlık yaptık onunla deneme, evlenmeden önce. Interbus [travelling Europe by bus] diye bir şey var, ona gittik, eşimle şey dedik hani, yapar mıyız, yapamaz mıyız? Ne yaparız, ne yaparız? Eşim dedi ki ben yaparım ya. Bir gazla çıkıp gerçekten orada çok başarılı geçti her şey hakikaten de. […] Ondan sonra da birçok şeyimiz kırıldı."[61]

Similarly, Damla could start being more open with her partner lately and could explain to him the things that she was keeping as a secret because they didn't look normal, such as how she uses the toilet, or could start asking for more help for the things she cannot do by herself. She explains the effects of these changes as follows:

> "Benim için çok şeyi etkiledi. Yani, ben bu kadar bilirse belki gider, hani hayatımın bu kadar zor olduğunu bilirse belki korkar diye düşünürken hiç değişen bir şey olmadı. Bu benim için iyi bir şey […] Hani şimdi de gayet normal bir şekilde devam ediyor. Biraz daha

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[61] "My partner made great efforts to learn my mother's method. Going to the toilet etcetera, like, what can we do without a patient lift? Let's say we go to bars, how can we use the toilet, what can we do in narrow spaces? We even did a crazy thing, a trial with him, before getting married. There is something called Interbus, we did it. We thought like can we do it or can't we? What can we do, how can we do? My partner said, 'I can do it'. Everything went really so good there. […] Then, many things have changed."

> güvenli bir şekilde, evet artık gerçekten bu adam var diyebileceğim bir noktada."[62]

In other words, having a unique relationship is possible through disabled people's accepting their own needs as they are. Moreover, these quotes indicate that disabled people start accepting their dependency on others' help when they realize that they can use the help of others to do things they want to do in their lives. However, it is still important to differentiate the acceptance of dependency on others' help from wanting to get this help from only one source, such as mothers, fathers, or partners, because it might increase the feelings of dependency, as it is explained by Ülkü as follows:

> "…acaba annemin yerine [eşimi] koymaya mı başladım falan diye korkmaya başladım. […] Bu sefer de eşimi [kaybedersem], duygusal olarak duygusal tabii bağ var da, tam duygusal bağ da değil de böyle. Bedensel bağ bile oluyor belki bilmiyorum, şey… şimdi mesela eşime var. Tam tabii ki anne gibi değil ama var tabi. Evet, çok aşırı bağlı olduğum insan bu dünyadan giderse ne yaparım? […] ki, ben nispeten bağımsız olduğumu düşünmeme rağmen."[63]

To sum up, the combination of several factors, such as disabled people's challenging their internalizations, their openness to new experiences and the presence of supportive relationships in their lives, leads disabled people to use the opportunities that will enable them to accept their physical realities. Therefore, as disabled people move towards embracing their unique ways of being, including their needs and solutions, they are less likely to long for normality. Instead, they expect that the society is arranged according to their needs for them to be included in the community and to fully enjoy their human rights. Therefore, some disabled

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[62] "It influences a lot of things for me. I was thinking like maybe he could go if he knew this much, he would be afraid if he knew my life is this hard and nothing happened. This is good for me. […] Now, it goes really normally. In a way that is more secure, in a way that I can say: 'yes, this man really exists'"

[63] "… I'm thinking whether I had replaced my mother with my partner. If I lose him… Emotionally, of course there is an emotional connection, but not totally emotional… It can even be physical dependency, I don't know, but I have it towards my partner. Not exactly like the one towards my mother, but yes, it exists. Yes, what would I do if the person I'm overly connected would leave this world? […] …though I think I'm relatively independent"

people prefer to actively fight against the discrimination that disabled people face on a regular basis. The impact area of this fight might range from individuals to community. For instance, Hande states that she warns non-disabled people who violate her rights, such as occupying the parking spaces for disabled people, whereas Ömer states that he uses his legal rights to change improper practices of the institutions. Similarly, Doğan explains that he has been active in disability rights activism for a long time, as well as providing guidance to people who become disabled as a result of spinal cord injuries. They express their feelings regarding their fight as follows:

> "Bir gün metroda gidiyoruz, şey çalışmıyor, rampa. Almışlar asansörü de sekiz basamak üste koymuşlar, güya engelli asansörü. Orada bütün güvenliklerin kavgaya geçecek kadar ileri gidecektim. İki hafta sonra arkadaşım bana Whatsapp'tan resim attı, 'abi nasıl bir adamsın, buraya rampa koymuşlar, şey, yürüyen platform koymuşlar'[64] (Ömer)

> "Mesela engelli aracıyla ilgili mevzuatı çok iyi biliyorum. Dernektekiler bana yönlendiriyor. Türkiye'nin her yerinden arıyorlar. Onlar hakkında bilgi veriyorum. Bildiğim ne varsa, engellilerin haklarıyla ilgili, ben genelde yardım ediyorum. Engellilerle ilgili ne varsa yardımcı olmaya çalışıyorum. Bu da beni mutlu ediyor. Bir şeye faydalı oluyorsam ne mutlu bize."[65] (Doğan)

All of these accounts indicate that disabled people's accepting their own reality, demanding their own rights and searching for the ways to make systematic changes in the society instead of longing for normality to be included in the community is possible, empowering, and effective to change the ableist system. Therefore, it is important to note that the adaptation of disabled people does not refer to their adaptation to the society. Rather, it refers to the disabled people's adaptation to their

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[64] "One day, I was in metro and the ramp wasn't working. The elevator is at the top of eight steps, so to say it's an elevator for disabled people. I was going to fight all the security guards there. Two weeks later, my friend sent me a photo over Whatsapp, 'geez, what kind of a man are you? They put a ramp here, I mean, walking platform'".

[65] "For example, I know really well the regulation of the vehicles for disabled people. People in our association direct the requests to me. They call me from every part of Turkey. I give information about it. Everything I know about the rights of disabled people, I usually help others. I try to help everything about disabled people. It makes me happy. If I am helpful for anything, I feel happy."

own physical realities by embracing their authenticity, while expecting the change from the society.

CHAPTER 4

DISCUSSION

The aim of this study was to examine the development of the self-concept of disabled people in relation to their body appearance and functionality. This examination was mainly conducted based on disabled people's experiences regarding their romantic relationships and sexuality. The first reason for focusing on romantic relationships and sexuality was their association with the body appearance and functionality. In addition, it is believed that these are one of the most important aspects of emerging adulthood and adulthood. The results of the qualitative analysis conducted with grounded theory perspective have yielded two paths leading to the feelings of shame or pride for the self-concept development of disabled people, although these are not categorical paths. Instead, each step of these paths is one of the two extremes of a continuum. Therefore, disabled people are not necessarily on one of the two paths nor are all the aspects of their lives at the same point. In fact, they move from one point to another from time to time. Following, the results about these two paths will be summarized and they will be discussed in the light of the characteristics of Turkish culture, which is believed to have a significant effect on the experience of disability.

The first path passes through the internalization of perfectionist and ableist norms in the society, which results from the interaction between the impairments and social barriers, including physical and attitudinal barriers. It is important to note that disabled people, whether they have congenital or acquired disabilities, are consistently exposed to these norms; and therefore, disabled people are forced to internalize them. However, individual differences, the quality of interpersonal relationships, the attitudes of strangers, and accessibility of the environment and services determine the level of internalization. When disabled people are in a disadvantaged position in all these areas, they are more likely to attribute the problem to the differences in their bodies, believing that they have a strange, dependent and burdensome body. In that case, they find the solution to their problems in becoming “normal” or non-disabled. Therefore, they are able to challenge neither the social barriers in the society nor their own internalizations. This process forms a vicious cycle, in which the social barriers and internalizations are strengthened whereas disabled people are weakened. Throughout this chapter, the relationship between this disabling vicious cycle, exclusion of disabled people from the society, and shame will be discussed. It is important to note that the existing literature on internalized ableism has been used and integrated into the constructed theory in order to make sense of the experiences of the participants of the current study.

The second path becomes possible when the disabling cycle can be broken. The first step to break this cycle is to remove the barriers against the inclusion of disabled people in the community. This refers to the changes in both built environment and social attitudes to disability. However, since this cannot be done easily, disabled and non-disabled people continue to be exposed to idealist and ableist norms in the society. This is the point where personal, relational, and environmental factors gain importance for this path. As disabled people have more positive character traits, supportive relationships with others, and access to the community life, they are more likely to start questioning and challenging their own internalizations of the perfectionist and ableist norms. By this way, they can start evaluate themselves apart from the societal perspective, which leads them to become a separate individual. This is mostly achieved by using the support provided by family members, friends, or partners, rather than professional assistants. As it will be discussed in this chapter, this might be the result of the Turkish culture, which emphasizes the importance to care for others as well as the lack of social arrangements which enable disabled people to hire personal assistants. However, it was found out that some disabled people can accept their physical needs being met by their families, friends, or partners without feeling psychologically dependent or like a burden to them. Therefore, they can begin to accept their impairments and their unique needs while they can build more adult relationships, as expected. Moreover, they can actively take part in disability rights activism, as they believe that what needs to change is the social barriers, including physical barriers and societal attitudes towards disability, nor their own bodies, which indicates that they reach to their authenticity. As a result, disabled people feel included, or at least they know that they will be included in the community as long as the social barriers are removed. This path is concluded with the pride, which will be discussed towards the end of this chapter.

1. Discussion of the Findings

1.1.Internalization of Idealist and Ableist Norms

The main finding of this study points out the significant role of disabled people's internalization of idealist and ableist norms in the maintenance of ableist cycle, beginning with the physical and attitudinal barriers in the society. This finding emphasizes the interaction between psychological and social factors in the experience of disability.

The finding regarding the internalization of body ideals leading to shame among disabled people is consistent with extensive research on appearance, which indicates that the internalization of body ideals is one of the main psychological factors leading to appearance dissatisfaction among adolescents and adults (Clark & Tiggemann, 2008; Myers & Crowther, 2009; Fitzsimmons-Craft; 2012; Arroyo, 2015; Trekels & Eggermont, 2017). These studies highlight the negative impacts of media and social comparison, imposing thin ideals, on individuals' evaluations of their bodies, which mainly result in body image concerns and body dissatisfaction, and also disordered eating in some individuals. It can be argued that this effect is even higher for disabled people, whose positive representations in the media are very limited. In fact, Barnes (1991, 1992) indicates that disabled people are mostly represented as non-sexual or undesirable in TV shows and movies, and the situation is worse for disabled women, whose experiences are almost ignored. In some of these depictions, disabled people’s lives are unworthy to live because they are not lovable. Such misrepresentations do not only affect non-disabled people’s perceptions about disabled people, but also disabled people’s self-representations through the impact of internalization. To the author’s knowledge, currently, there aren’t any studies investigating how the appearance, romantic relationships, and sexuality of disabled people in Turkey are represented in the media and popular culture. However, the findings of this study indicate that disabled people in Turkey are also exposed to the messages idealizing the bodily perfection and are inclined to see the differences in their bodies as a reason for rejection in their romantic relationships and sexuality. Moreover, the perceptions of disabled people are supported by their personal experiences with their previous potential or actual partners, who have put forward their partner’s disabilities as a reason for ending their relationship.

The finding regarding the internalization of ableist norms leading to shame is also consistent with the previous studies explaining the effects of ableism and internalized ableism. For instance, Overall (2006) states that ableism imposes uniformity as the norm and assimilates people who cannot or don’t conform to the ableist norms. In other words, in an ableist society, disability is shameful and should be avoided to have a value in the society. In fact, this *compulsory ableness* leads to the internalization of ableism (Campbell, 2008). However, although it is mostly stated that in Turkey disabled people are seen as objects of pity and passive recipients of the help provided by non-disabled people, who cannot have independent lives, there is still limited research on how disability is perceived in the mainstream culture. For instance, Aslan and Şeker (2011) have found out that disabled people are widely excluded from the society as a result of negative perceptions about disability. Bezmez and Bulut (2016) have investigated the representations of disabled people in the television shows on health and revealed that the representations of disabled people varied between three categories: disability as a familial, religious, or medical issue. In fact, these findings are consistent with the social structure of Turkish society, which is mainly under the influence of collectivistic cultural values and religion (Cukur, Guzman, & Carlo, 2004). Moreover, Kara (2007) notes that paternalistic characteristics are very common in Turkish culture. These might be the factors reinforcing society's approach to disability as a personal tragedy that requires help from others.

The findings of this study indicate that as compared to the body ideals of the society, ableist norms influence more aspects of disabled people's lives, including their professional life and marital life, as well as romantic relationships and sexuality. Their experiences of being excluded from work or not being seen as appropriate for marriage are the results of ableism in the society. In fact, it is remarkable that the presence of physical impairments is associated with the limitation in disabled people's roles in the society attributed according to their genders. For instance, disabled men in the current study express that they face more problems related to their professional life whereas disabled women express that they face more problems related to their appearance and ability to do housework. Combined with the physical and institutional barriers, the presence of such norms threatens the existence of disabled people and undermines their economic, cultural, social and emotional lives (Loja et al., 2013). Here, it is worth noting that in Turkey, education and employment rates are lower in disabled people as compared to non-disabled people, with a higher rate of illiteracy and dropouts from school (DIE, 2002). Moreover, accessibility is still one of the biggest problems in Turkey (Çağlar, 2012). Therefore, in a society that is structurally and socially designed for non-disabled people, disabled people experience difficulties in rejecting ableism and become more susceptible to internalization of ableist norms, which prevents them to form a collective culture of disability by distancing them from other disabled people (Campbell, 2001). These might be several reasons why there is a lack of right-based movement in the disability field in Turkey (Bezmez & Yardımcı, 2010).

The accounts of the participants of the current study reflect how they have normalized the societal perspective towards their disabilities, especially when they state that they can understand why their partners or their partners' families reject them blaming their disabilities. In fact, when they state that way, it is seen that they also blame their dependency to help, which makes them feel like a burden to others. However, the main problem is the lack of social arrangements that will enable disabled people to live independently in Turkey. In other words, if their right for living independently and being included in the community can be applied as it should be, by ensuring their access to residential and community support services, as well as the use of personal assistance, then they will be able to use the support they are provided to improve their self-esteem, instead of feeling inferior or like a burden to others just because they need physical assistance to care for themselves. However, because of several cultural factors that will be discussed in the following section, independent living in Turkey is not even an option for many disabled people, which strengthens the internalization of ableist norms in the society.

1.2.Psychological Growth Through Independent Living

The results of this study reveal that people with physical disabilities in Turkey, particularly the ones who live in the community, have support for their daily needs mostly from their families or partners. Only one participant has the experience of hiring a personal assistant. In fact, this kind of support is not preferred because participants believe that the need for personal assistance is associated with higher levels of dependence to help from others, which is perceived as a sign of weakness, as it was explained above. On the other hand, the only participant living with a personal assistant expresses the difficulties in finding someone whom she is comfortable with, which make her worried about her level of dependency that might cause her assistant leave the job because she believes that she is very burdensome. All of these difficulties might be the results of the lack of arrangements regarding the right for living independently and being included in the community, such as the system of personal assistance and independent living centers, in which there is a pool of candidates who want to work as a personal assistant, and to which disabled people can apply to meet with the candidates.

In America and other Western countries, there have been numerous studies conducted to examine psychological consequences of arrangements that enable independent living for disabled people, including the system of personal assistance. These studies mainly emphasize the importance of disabled people's having the opportunities of control and choice over their decisions regarding their lives. As Schaefer (1995) has found out, disabled people who don't have access to independent living feel like physically and economically burden to others and believe that their social functioning is lower than others. In line with this, several studies also have revealed that caregivers who are not officially employed such as family members or relatives are forced to take lots of responsibilities and to make several changes in their lifestyles and roles in the families (Boström, Ahlström, & Sunvisson, 2006; Jumisko, Lexell, & Söderberg, 2007). In other words, the relationship between disabled people and their families and relatives are inevitably affected by the additional role of caregiving. On the other hand, Stainton and Boyce (2004) have revealed that disabled people who employ their own personal assistants express higher levels of trust and comfort because they have the opportunity to control the support they are provided for their daily needs. Moreover, they have higher self-esteem and more profound relationships with others, enabling them to be more effective in their personal and professional lives. It has also been stated that disabled people's relationships with family members and relatives improve as a result of the increased flexibility in their lives. Similarly, Nosek, Fuhrer and Potter (1995) have found out that having support from personal assistants is associated with higher levels of life satisfaction of disabled people, regardless their levels of dependency. These studies point out the positive impact of disabled people's having the opportunity of control and choice over the support they are provided on their psychological well-being.

On the grounds of the studies summarized above, considering the lack of understanding of independent living and personal assistance system in Turkey, disabled people's concerns about their dependency to others' help becomes clear. In fact, regardless of the fact that they live with their parents, with their partners, or alone, participants express feelings of guilt for the burden they cause to their caregivers. Moreover, some of the accounts reveal that needing support from partners resulted in role confusions during their relationships, in which partners felt that they wouldn’t be able to carry the burden of having a partner with disability. As it can be seen, these factors limit the right for independent living of disabled people and strengthen the ableist barriers that prevent them to be included in the community equally with others. In fact, as one of the participants explained, accessible car arranged at the university to take students to their classes and to their homes was the one of the services that supports independent living of students with disabilities. By this way, students with disabilities are able to access to their classes equally as their peers without feeling dependent to their families or friends. However, it is clear to see that disability support services in Turkey do not attach great importance to the independence of disabled people. Following, the possible reasons and consequences of this situation will be discussed.

The traditional collectivist values and religiosity of Turkish culture might influence non-disabled people’s approaches to independent living. To begin with, collectivism is associated with strong family ties, which are maintained through paternalistic attitudes, where younger members get love and care whereas older members get respect and authority (Kara, 2007). From this perspective, disabled people are in a position where they need constant support from other members. Moreover, having support from someone outside the family is a shame for the entire family. This perception is also reinforced by the religious beliefs that taking care of the ones who are in need is a religiously virtuous act. Moreover, although other cultures perceive disability as a divine punishment, the results of the survey “How Society Perceives Persons with Disabilities?” (Administration for Disabled People, 2009) have revealed that disability is seen as a divine exam in the Turkish society. Therefore, families with disabled members take all the responsibility of caring for the member with disability to become successful in this exam.

As a consequence, Turkish cultural background might force disabled people to stay in an infantilized position and interrupt their separation and individuation process, especially among people with congenital or early-onset disabilities. However, as acquired disabilities require adaptation to the differences in the appearance and functionality of the body, people with acquired disabilities are also faced with the challenge to gain their autonomy back. In fact, many personality theories emphasize the importance of separation and individuation from primary caregivers for healthy psychological development. For instance, Erikson (1950, 1963) describes this process as a result of child's increased mobility, which enables them to become more independent and autonomous in their actions. At this stage, if the child is supported, rather than being criticized or overprotected, they will become more confident about their own ability to survive. Otherwise, they will experience the feelings of inadequacy, dependency to others, shame and doubt in their abilities (as cited in Feist & Feist, 2008). According to the results of few studies conducted on the separation-individuation process of children with disabilities, this process might be interrupted as a result of their physical or sensory impairments, which interfere with the processing of and reacting to the external stimuli, or their parents' reactions to the physical and sensory impairments of their children, such as rejecting their needs or overprotecting (Mordock, 1979; Ozhek, 2007). Moreover, the separation-individuation process is not completed at the end of this stage. Instead, it continues during adolescence and adulthood, at the end of which individuals are expected to maintain their relationships with their parents in a healthy way, to develop their own identity, to take their own responsibilities, and to form adult relationships (Koepke & Denissen, 2012). In fact, Erickson (1950, 1963) emphasizes the role of forming friendships, initiating activities, achieving goals, exploring personal values, beliefs and goals, and determining one's role in the society in order to reach to adulthood, whose the main task is to form intimate adult relationships (Feist & Feist, 2008). As it can be seen, the positive consequences of the process of separation-individuation is closely related with the principles of independent living movement, including having freedom to make decisions about one's own life and to develop one's own individuality, while forming relationships equally with others.

The findings of the current study support the importance of separation-individuation process for the psychological growth of disabled people. In fact, both parents and their disabled adult offsprings worry about their future opportunities to get help, especially when their parents will be no longer available to provide that support. It has been found out that separation-individuation process decreases the worries and anxieties about the future and gives them the confidence that they can keep surviving. This enables disabled people to review their relationships with their parents and to form an adult relationship, which is not based on their dependency to the help of their parents. Moreover, the accounts of disabled people indicate that friends and partners with or without disabilities play a significant role in their explorations of their limits regarding their own capabilities and the ways to overcome their limitations. At that point, when they are more likely to question and challenge the idealist and ableist norms in the society, they can engage in romantic relationships, which trigger the individuation-separation conflict once again, because many of the participants express their needs to be independent as much as possible in order to decrease the burden to their partners caused by their dependency. However, it is noteworthy that many disabled people do not consider of having a personal assistant due to economic or practical reasons, such as not feeling ready for that or believing that their parents and partners are better caregivers. It can be argued that the lack of independent living as a systematically arranged option in the society, disabled people experience difficulties in taking steps to become more independent.

In sum, whether they have congenital or acquired disabilities, disabled people face a lot of barriers during each stages of their psychosocial development in a society which is structurally and socially arranged for non-disabled people, and in which disabled people are infantilized and seen as the passive recipients of the help. Moreover, the lack of social arrangements supporting independent living of disabled people is another barrier against their inclusion in the community equally with others. This is one of the factors that lead to the internalization of shame and struggles to feel pride among disabled people.

1.3.Exclusion/Inclusion and Shame/Pride

Rights-based movements in disability field aims to ensure the inclusion of disabled people in the community equally with others. Although the concepts of “exclusion” and “inclusion” are frequently used in educational settings, for the scope of this study, it is important to provide their definitions in a broader sense. Petrovic (2013) defines the term “social exclusion” as “*a process that prevents certain individuals from participation fully in relevant social, economic, cultural, and political aspects of life*” while “social inclusion” as “*the process that prevents people from becoming excluded and provides them with the opportunities for greater participation in the society*”. Therefore, in the light of the results of this study, it is safe to say that disabled people’s participation in various aspects of life is restricted as a result of physical barriers, idealist and ableist norms in the society, disabled people’s internalization of these norms, and lack of social policies to ensure their inclusion in Turkey. In other words, disabled people are excluded from education, employment, public life, cultural life, and recreational, leisure, and sports activities. Although exclusion appears to be the consequence of the ableist cycle, it also contributes to the maintenance of this cycle because it prevents disabled people’s empowerment, strengthens their internalization of the society’s perception of disabled people, and forces them to have and accept an inferior position as compared to non-disabled people. As Rukgaber (2016) discusses, this inequality within the society is associated with the feelings of shame, most of which are internalized and are not overtly verbalized but become apparent when disabled people attribute the reasons for rejection, humiliation, and exclusion to their physical disabilities. These might explain why people start longing for normality when they are faced with discrimination and exclusion from the society.

These findings are also consistent with the results of previous studies, indicating the importance of the inclusion on the empowerment of children and adults with disabilities (Hutzler, Fliess, Chacham & Van den Auweele, 2002; Burton, Sayrafi, & Srour, 2013). Moreover, the accounts of the participants indicate that inclusive environments, either university, work, or friend circles, enable them to accept their needs without denying, ignoring, or hiding them, and therefore, let pride take the place of shame. In fact, many disabled people claim their disabilities as a part of their identity. In that context, disability pride can be defined as being proud of one's own physical characteristics that are mostly rejected in the society, and accepting these characteristics as variations in human existence (Hahn, 1997; Putnam, 2005). In addition, disability pride encompasses the acknowledgement that inclusion can be and should be achieved through removing physical and social barriers in the society, not by changing appearance and functionality of disabled people. These result in disabled people's psychological openness to be included in disability community (Dunn & Burcaw, 2013), in which they can resist against the barriers in the society. In line with these explanations, some participants of this study also demonstrate signs of pride, although they do not call their feelings as pride. For instance, they state that currently, they are more open to their own needs than before. Similarly, some of them express that they do not hide their needs in their intimate relationships anymore and expect to be accepted with the reality of their bodies. At this point, in order to feel more included in the community, some of them request that the society is arranged according to their needs. These requests might be ranging from personal to organizational level; however, it is important to note that these right-based requests to be included in the community commonly come from disabled people who can start rejecting the idealist and ableist norms in the society and accepting their bodies as they are. Therefore, although disabled people are not really included in the community with the continuing presence of physical and attitudinal barriers in the society, as it is the case in Turkey, those who get and use the opportunities to question the main reasons for their exclusion and challenge idealist and ableist norms in the society can become hopeful about the future because they do not feel the need to change their bodies for this anymore. Instead, they focus on what can be really changed: the society.

Considering the fact that right-based movement of disabled people in Turkey is very limited, it is safe to say that mainstream culture that is based on collectivism and religiosity, limited participation of disabled people in education, employment, and public and cultural life as a result of physical and attitudinal barriers, limited access to independent living options, and disabled people's internalizations of idealist and ableist norms in the society are impeding factors for the development of disability pride among disabled people. Therefore, in order to ensure disabled people's full enjoyment of their fundamental rights and freedoms and equal participation in the community life in Turkey, necessary adjustments and accommodations should be made and interventions on disability awareness and disability equality targeting both non-disabled and disabled people should be developed.

2. Implications of the Study

To the best of the author's knowledge, the current study is the first qualitative study investigating disabled people's psychological experiences of disability with a focus on their body appearance, body functionality, romantic relationships, and sexuality, conducted in Turkey from an insider's perspective. Moreover, the findings of this study emphasize the most overlooked subjects in disability field in Turkey; independent living and disability pride, both of which have valuable practical and clinical implications.

2.1.Practical Implications

The findings of this study mainly point out the interaction between social and psychological factors preventing the inclusion of disabled people in the community. In line with other studies conducted on the disabling effects of physical and social barriers on the lives of people with impairments in Turkey (Özbulut & Özgür Sayar, 2009; Özgökçeler & Bıçkı, 2010; Genç, 2015), the current study underlines the urgent need to remove the physical and social barriers in the society in order to ensure full participation of disabled people in the community equally with others. Besides, the main findings regarding the internalization of idealist and ableist norms in the society emphasize the importance of disabled people's empowerment. As Burcu (2011) has found out, especially disabled people who don't have access to education and employment are in a disadvantaged position, where they are more likely to be exposed to negative perception towards disability and disabled people.

Therefore, information regarding fundamental rights and freedoms of disabled people from a social perspective to disability should be provided to both non-disabled and disabled people. In fact, nowadays, in Western countries, there are many trainings on disability awareness or disability equality in schools conducted by experts in disability field. The implementation of such trainings in Turkish schools, workplaces, or public education centers might enable children and adults with or without disabilities to understand disability as a human variation. Moreover, revisions on the representations of disabled people in the mainstream media are necessary to challenge idealist and ableist norms. In fact, such interventions would not only be beneficial for disabled people, but also for non-disabled people because they will promote body diversity and body acceptance, which are associated with higher levels of psychological well-being (McKinley, 2004; Swami, Weis, Barron, & Furnham, 2017).

Another important practical implication of the current findings is the need for independent living opportunities for disabled people in Turkey. Actually, the fact that there are no arrangements regarding independent living of disabled people in Turkey is a violation of the right for living independently and being in the community stated in the UN CRPD, which was ratified by Turkey in 2009. As the findings of this study indicate the lack of acknowledgement of independent living as a fundamental right is a disabling factor, in the sense that people with physical disabilities are forced to live with their parents or partners if they want to continue to live in the community. Otherwise, the only option for people with physical disabilities who are not able to meet their needs without any help is institutions, which leads to a greater violation of the aforementioned right. Moreover, independent living opportunities are believed to be beneficial both for disabled people and their families, relatives, and partners because they will give them flexibility in their lives, as disabled people will be able to have support from a professional when their “caregivers” are not available in the present day or in the future. Therefore, it is important to start requesting arrangements to ensure independent living of disabled people and discussing how independent living can be implemented in a way that fits Turkish social security system, in order to make sure that disabled people are fully included in the community.

Lastly, the current study demonstrates the importance of the development of disability identity based on pride, which becomes possible through the empowerment of disabled people. Only this way can disabled people adopt a right-based perspective towards their disabilities. In fact, many associations on disability in Turkey work for disabled people, with a charity perspective. Therefore, the need for associations of disabled people, led with social rights perspective by disabled people themselves, still persists. These have utmost importance in order to protect the dignity of disabled people, while ensuring their full enjoyment of their fundamental rights and freedoms.

2.2.Clinical Implications

The findings of the current study have very important clinical implications as well. First of all, although clinical psychology and disability studies have always been regarded as distinct fields of practice and research, this understanding has been lately changing. In this sense, the current study, examining personal experiences of disability, is another brick on the bridge between these two fields. The qualitative nature of this study provides rich and detailed information on how physical disability is experienced in relation to body appearance and functionality in a society idealizing normality. Moreover, this study presents the psychological consequences of the lack of understanding about independent living among both non-disabled and disabled people, including internalization of idealist and ableist norms. Considering the contribution of these internalizations to the vicious cycle formed with physical and social barriers and longing for normality, the need for developing interventions targeting empowerment of disabled people becomes clear. These interventions should focus on questioning and challenging idealist and ableist norms in Turkish culture, including the ones regarding romantic relationships and sexuality of disabled people. In fact, discussions on these topics are vital in disabled people’s lives because they are important aspects of healthy adulthood. Therefore, this study is one of the few studies conducted in Turkey (see Döner, 2015), reminding both non-disabled and disabled people of the fact that disabled people are sexual beings, just like anyone else. Lastly, the findings of this study give insight on the development of shame and pride among disabled people as a reaction to a society structurally and socially designed for non-disabled people, and their possible effects on the maintenance or challenging of the current ableist social structure.

Overall, this study contributes to the understanding of the experience of disabled people in Turkey both from psychological and social perspectives, which can be helpful for the professionals conducting individual or group interventions with people with physical disabilities, whose problems would be inevitably influenced by this overall experience of disability. Based on the findings of this study, it can be recommended to professionals who work with physical disabilities to question their own assumptions about disability and disabled people and to understand disability as an experience that is associated with both personal and social factors, beyond from personal tragedy or medical perspective. Furthermore, the level of separation-individuation of disabled people should be evaluated and separation-individuation and independent living should be among the focal points of psychotherapy processes in order to ensure their full and equal participation to the society. For these purposes, interventions for the families and partners of disabled people should also be developed because separation-individuation is a reciprocal process. Lastly, it is important to note that the aim of psychotherapy with disabled people, as it is the case with everyone else, should be to find their authentic selves, rather than finding ways to conform to whatever is seen as “normal”.

3. Limitations of the Study

Besides the strengths described above, this study has some limitations that might have had potential effects on the nature of the collected data and the generated theory at the end. First of all, for the practical purposes, only one interview was conducted with each participant. Moreover, although some participants could easily provide in-depth information, others might have needed more than one interview to access to the deeper emotional content regarding their experience of disability. Still, the researchers (Ünal and Gençöz) evaluated these differences as the results of individual differences in the experience of disability. Second, although grounded theory is a methodology that is open to the use of different types of materials, such as autobiographies, journals, and other documents with an aim to richen the data, the current theory was constructed only on the data gathered from the semi-structured interviews. In fact, this limitation is associated with the third one: in grounded theory, researchers also have the opportunity to include participants with different characteristics, including the ones that do not meet the initial inclusion criteria (Charmaz, 2008). For instance, in the current study, it would have been possible to include parents or partners of disabled people in order to better understand the effects of having an adult offspring or partner with disability on their lives. The main reason for not relying on other types of data or other sources was the time constraint. However, the current amount of qualitative data was found sufficient for the first study conducted on this topic in Turkey. Researchers believe that the theory constructed at the end can be improved through the use of these strategies in the future.

4. Directions for Future Studies

Although this study focused on the experiences of disabled people who constantly use wheelchair, body perception, romantic relationships, and sexuality, and their influences on the sense of self among people with less severe physical disabilities or other types of disabilities could provide better insight on the similarities and differences between the experiences of disability within these groups. Moreover, in order to better understand families' reactions towards disability of their children with disabilities and the consequences of these reactions on the separation-individuation process of their children with disabilities, studies investigating the relationship between parents and their children or adult offsprings with disabilities could be beneficial. In addition, although this study mainly focuses on the feelings of shame and pride, people with physical disabilities might be struggling with the presence of other negative emotions such as sadness, worry, anxiety, and anger. Therefore, future studies focusing on the causes and consequences of these emotions for the lives of disabled people might enable researchers and practitioners to better understand the personal experience of disability. Lastly, studies focusing on disabled people's understanding of independent living would enable professionals in field of disability rights to recognize disabled people's needs and expectations about this topic, which would be important for implementing independent living in a way that meets the needs of disabled people in Turkey.

5. Conclusions

The aim of this study was to investigate the personal experiences of disability among people with physical disabilities in relation to the appearance and functionality of their bodies, with the main focus on their romantic relationships and sexuality. The findings revealed the importance of internalization of idealist and ableist norms in the society on the maintenance of ableist system and the importance of becoming a separate individual through questioning and challenging these norms and becoming independent from family and society to reach to their authenticity. In fact, this is how disability shame is replaced with pride and disabled people can start fighting to move from exclusion to inclusion in the community. It is important to note that these findings should be evaluated along with the strong collectivist and religious structure of Turkish culture, as well as the ableism that is prevalent in the Turkish society. To conclude, in order to protect the dignity of disabled people and to ensure their full inclusion in the community, certain measures should be taken at both individual and social levels.

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APPENDICES

APPENDIX A: ANNOUNCEMENT FOR THE STUDY

Orta Doğu Teknik Üniversitesi Psikoloji Bölümü Klinik Psikoloji Doktora Programı öğrencisi Uzm. Psk. Beyza Ünal tarafından, fiziksel engelli bireylerin beden algısını ve beden algısının kişilerarası ilişkiler üzerindeki etkisini anlama amacıyla doktora tezi olarak yürütülen bir çalışma için, aşağıdaki özelliklere uyan katılımcılara ihtiyaç duyulmaktadır:

1. 18-65 yaşları arasında olmak
2. Doğuştan gelen ya da kaza, hastalık, yanlış tıbbi müdahale vb. gibi nedenlerle fiziksel engelli durumda olmak
3. Fiziksel engeli nedeniyle sürekli olarak tekerlekli sandalye kullanmak
4. Fiziksel engelinin dışında herhangi bir görme, işitme ya da zihinsel engele sahip olmamak

Çalışma kapsamında katılımcılarla yaklaşık 1-1.5 saat sürecek olan bir görüşme yapılacak olup katılım tamamen gönüllülük esasına dayanmaktadır. Çalışmaya katılmak ya da daha fazla bilgi almak için lütfen beyza.unal@metu.edu.tr adresinden ya da 0555 677 3223 numaralı telefondan araştırmacıyla iletişime geçiniz. Teşekkür ederiz.

APPENDIX B: INFORMED CONSENT FORM

Bu çalışma, Orta Doğu Teknik Üniversitesi Psikoloji Bölümü Klinik Psikoloji Doktora Programı öğrencilerinden Uzm. Psk. Beyza Ünal tarafından, öğretim üyesi Prof. Dr. Tülin Gençöz danışmanlığında yürütülmektedir. Çalışmanın amacı, fiziksel engelli bireylerin kendilik ve beden algılarına ilişkin niteliksel bilgi toplamaktır. Bu kapsamda, 30 fiziksel engelli bireyle yarı yapılandırılmış bireysel görüşmeler yapılması planlanmaktadır. Her katılımcıyla yalnızca bir görüşme yapılacak olup bu görüşmenin yaklaşık olarak 1,5 saat sürmesi beklenmektedir.

Bu çalışmaya katılım gönüllülük esasına dayanmaktadır. Görüşme soruları içerisinde, katılımcılara rahatsızlık verecek herhangi bir soru bulunmamaktadır. Buna rağmen, herhangi bir nedenden dolayı çalışmaya katılmayı reddedebilir ya da çalışmayı yarıda bırakabilirsiniz.

Bu çalışma süresince toplanan veriler tamamen gizli tutulacak ve veriler kimlik bilgileriyle eşleştirilmeyecektir. Elde edilen bilgiler yalnızca araştırmacılar tarafından ulaşılabilecek ve yalnızca bilimsel ve profesyonel amaçlı yayınlarda kullanılacaktır.

Araştırmayla ilgili daha fazla bilgi almak isterseniz, araştırmacı Uzm. Psk. Beyza Ünal'a (e-mail: beyza.unal@metu.edu.tr) ya da danışman öğretim üyesi Prof. Dr. Tülin Gençöz'e (e-mail: tgencoz@metu.edu.tr) ulaşabilirsiniz.

Yukarıdaki bilgileri okudum ve bu çalışmaya tamamen gönüllü olarak katılıyorum (Formu imzaladıktan sonra araştırmacıya geri veriniz)**.**

Ad-Soyad	***Tarih***	***İmza***
……………	……………	
……………		

APPENDIX C: QUESTIONS OF THE SEMI-STRUCTURAL INTERVIEW

Katılımcı Numarası:

Cinsiyet:

Yaş:

Medeni Durum:

Eğitim Durumu:

Meslek:

1. Fiziksel engelinizden bahseder misiniz?
2. Fiziksel engeliniz hayatınızı nasıl etkiliyor?
   - Fiziksel görünüşünüzü nasıl değerlendiriyorsunuz?
     - Bedeninizin en sevdiğiniz/en sevmediğiniz/farklı olmasını isteyeceğiniz yönleri nelerdir?
     - Diğer fiziksel engelli ve fiziksel engelli olmayan bireylere kıyasla nasıl bir görünümünüzün olduğunu düşünüyorsunuz?
     - Görünür bir engele sahip olmak bedeninizi algılayışınızı nasıl etkiliyor?
     - Fiziksel görünümünüze uyum sağlamanızı kolaylaştıran/zorlaştıran faktörler nelerdir?
   - Engelli bir kadın/erkek olmak sizin için nasıl bir deneyimdir?
3. Engelli bir birey olarak…
   - Kendinize bakışınız/tutumunuz/davranışlarınız nasıldır?
   - Başkalarının size bakışı/tutumu/davranışları nasıldır?
4. Hayatınızda fiziksel engelinizin neden olabileceği olumsuz durumlarla baş etmenizi kolaylaştıran neler olabilir?

APPENDIX D: CURRICULUM VITAE

PERSONAL INFORMATION

Surname, Name: Ünal, Beyza
Nationality: Turkish (TC)
Date and Place of Birth: 25.02.1987 / Ankara
email: beyza.unal@metu.edu.tr

EDUCATION

Degree	Institution	Year of Graduation
MS	METU Clinical Psychology	2012
BS	METU Psychology	2010
High School	Atatürk Özel Tevfik Fikret Lisesi	2005

WORK EXPERIENCE

Year	Place	Enrollment
2017 - Present	ENIL Youth Network	Board Member
2015 - Present	Dönence Psikoterapi	Clinical Psychologist
2012 - 2015	Hacettepe University Psychological Counseling Center	Clinical Psychologist

FOREIGN LANGUAGES

Advanced English, Advanced French

PUBLICATIONS

Ünal, B., Ar, Y., & Gençöz, T. (2017). Etkin bir süpervizyon süreci neleri kapsamalıdır? Türk klinik psikologların gözünden psikoterapi süpervizyonu. *AYNA Klinik Psikoloji Dergisi, 4*(2), 48-64.

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APPENDIX E: TURKISH SUMMARY/TÜRKÇE ÖZET

BÖLÜM I: GİRİŞ

Bu araştırma, Türkiye'de yaşayan fiziksel engelli bireylerin beden görünümleri ve işlevsellikleriyle ilişkili olarak gelişen kendilik algılarını anlamlandırmak amacıyla yürütülmüştür. Bu nedenle, bu bölümde engelliliğin geleneksel ve çağdaş kavramsallaştırması, bedenselliğin bu kavramsallaştırmalardaki rolü, beden görünümü çalışmalarının engellilik çalışmalarına etkisi ve bahsedilen psikolojik ve fizyolojik etmenlerin engelli bireylerin deneyimleri üzerindeki sonuçları aktarılacaktır.

1. Engellilik

1.1.Engellilik Kavramının Tarihsel Gelişimi

Günümüzde, dünya genelinde engelliler, engelli olmayan bireylerle eşit hak ve fırsatlara sahip olabilmek için hak temelli bir mücadele sürdürmektedirler. Ancak, tarih boyunca, engellilik kavramının toplumdaki normatif standartlar üzerinden değerlendirilerek kişisel bir trajedi ya da tıbbi bir durum olarak algılandığı bilinmektedir (Barnes, 2012). Örneğin, ilk ve orta çağlarda, fiziksel sakatlıkların şeytani bir özellik ya da ilahi bir ceza olduğuna inanılmış ve bu nedenle, bazı dönemlerde sakatlığı olan bireyler öldürülmüştür. Bilimsel gelişmeler ve sanayi devriminin sonucunda ise, sakatlıkların tıbbi bir durum olduğu anlaşılmış; ancak, sakatlığı olan bireyler, üretime katkı sağlayamadıkları düşünülerek toplumdan ayrıştırılmıştır (Braddock & Parish). Dolayısıyla, engelliler, kendi hayatları üzerinde hiç kontrol ve seçim olanağının olmadığı yatılı bakım merkezlerinde kalmaya zorlanmış, ancak Avrupa, Avustralya ve Amerika'da eş zamanlı olarak başlayan hak mücadeleleri sonucunda engelliliğin yeniden tanımlanmasını sağlamışlardır (Oliver, 1996). Dolayısıyla engelliliğin sosyal modeli, asıl engelleyici olanın bireylerin fiziksel sakatlıkları değil, toplumun dışlayıcı ve ayrıştırıcı özellikleri olduğunu, engellilerin toplumda baskı gören topluluklardan olduğunu ve bunun toplumsal yaşamın her alanında karşılaştıkları ayrımcılıktan kaynaklandığını vurgulamaktadır (UPIAS, 1976). Bununla birlikte, engelliler kendi hayatları üzerindeki kontrol ve seçim olanaklarını elde edebilmek için Bağımsız Yaşam Hareketi'ni başlatmış ve şu an birçok ülkede uygulanan bağımsız yaşam şemalarının gelişimine katkıda bulunmuşlardır (Hayashi & Okuhira, 2008; Brennan, Traustadottir, Rice, & Anderberg, 2016). Bütün bu hakların sağlanmasında, aynı zamanda Türkiye'nin de imzalayıp onayladığı Birleşmiş Milletler Engelli Hakları Sözleşmesi'nin yürürlüğe girmesinin önemli bir etkisi bulunmaktadır (UN, 2006). Bir sonraki bölümde, sosyal modelin engellilerin hayatındaki öneminin daha iyi anlaşılması adına, bireysel ve sosyal modellerin arasındaki farklar tartışılacaktır.

1.2.Engelliliğin Bireysel ve Sosyal Modelleri

Trajedi modeli ve tıbbi modeli içeren engelliliğin bireysel modellerine göre, sakatlıkların kendisi, engellilerin toplumdan ayrıştırılmaları ve dışlanmalarının temel nedenidir. Dolayısıyla, trajedi modeli, engellilerin yaşamlarını ancak başkalarına bağımlı olarak sürdürebileceğini savunurken, tıbbi model engellilerin topluma dâhil olabilmeleri için tıbben iyileştirilmeleri gerektiğini belirtmektedir (Oliver, 2013). Öte yandan, sosyal model, engellilerin topluma dâhil olma sorununun kaynağının engelleyici fiziksel düzenlemelerde olduğunu ve engellilerin toplumda dezavantajlı bir konumda kaldığını vurgulamaktadır. Böyle bir bakış açısının, engellilerin bireysel deneyimlerini daha iyi yansıttığı görülmüş ve sosyal model, hak temelli mücadelelerin ortaya çıkmasını sağlayarak, politik ve sosyal değişim için kullanılan bir araç haline gelmiştir (Campbell & Oliver, 1996). Ancak, bazı yazarlar, sosyal modele odaklanmanın, engelliliğin kişisel boyutlarının göz ardı edilmesine neden olduğu yönünde eleştiriler getirmiştir (Oliver, 2013). Bu nedenle, bir sonraki bölümde, engellilik çalışmalarındaki güncel tartışmalar gözden geçirilecektir.

1.3.Bireysel ve Sosyal Modellerin Ötesi

1.3.1. Bedenselleştirme

Engelliliğin sosyal modeline yönelik eleştiriler, genel olarak bu modelin engelliliğe dair kişisel deneyimleri içermediği ve bedensel sakatlıkları yalnızca biyolojik farklılıklara indirgeyerek, bedenin kendilikten ayrı bir nesne olarak değerlendirdiği fikri üzerinde durmaktadır (Morris, 1991; Shakespeare, 2014; Hughes & Paterson, 1997). Bu nedenle, engellilik teorisinde, bedene ve sakatlığa dair tartışmalar tekrar ortaya çıkmıştır.

Bu tartışmaların bir yönü, sakatlığın, engellilerin hayatına doğrudan etkisine odaklanmaktadır. Bu, anlamlı bir kavramsallaştırmadır çünkü engelleyici düzenlemeler yalnızca sakatlığı olan bireyler için engelleyicidir (Thomas, 2012). Öte yandan, sosyolojik araştırmalar, bedenin bireylerin içsel yaşamlarını anlamak için bir kaynak olmasının yanında, toplumda "ayrıcalıklılık, statü ve güç" göstergesi olduğunu vurgulamaktadır (Turner, 2001; Garland Thompson, 1997). Engellilik çalışmaları da, toplumda kabul edilen beden normlarının sorgulanmasına katkıda bulunmuş ve "normal" görülmediği için dışlananlara söz hakkı tanınmasına yardımcı olmuştur (Lisi, 1994; Zitzelsberger, 2005).

1.3.2. Sağlamcılık ve İçselleştirilmiş Sağlamcılık

Sağlamcılık ve içselleştirilmiş sağlamcılık, engellilik literatüründeki görece yeni kavramlardandır. Toplumda sağlamcı normların varlığı, tercih edilen bir "sağlam" kategorisinin yaratılmasına ve sakatlığı olan bireylerin değersiz görülmesine neden olur (Campbell, 2008). Bu normlar, aynı zamanda yasal ve yönetimsel yollarla güçlenmektedir (McRuer, 2006; akt. Harnish, 2017). Bununla birlikte, engeli olmayan bireyler için düzenlenmiş bir dünyada, tüm bireyler sağlamcı mesajlara maruz kalmaktadur. Bunun sonucunda, engelliler de, engelliliğe dair önyargıları içselleştirebilmekte ve kendilerini değersiz hissedebilmektedirler. Bu durum, engellilerin toplumdan dışlanmalarını kabul etmesine neden olarak, engellilik kültürünün oluşmasını güçleştirmektedir. Bu nedenle, engellilerin haklarının sosyal model çerçevesinde savunulması için, engelliliğin psikolojik ve duygusal yönlerinin anlaşılması önemli görülmektedir (Watermeyer & Swartz, 2008).

1.3.3. Engellilik Çalışmaları ve Klinik Psikoloji

Son döneme kadar, klinik psikoloji, bireyselliğe vurgusu nedeniyle, disiplinlerarası bir alan olan engellilik çalışmalarında yeterince yer bulamamıştır. Günümüzde ise, araştırmacılar engellilerin güçlendirilmesi yoluyla toplumsal değişimi kolaylaştırabilmek için klinik psikolojiden faydalanmaktadırlar (Goodley & Lawthorn, 2006; Meekosha & Shuttleworth, 2009). Bu işbirliğinin hem engellilik çalışmalarına hem de klinik psikolojiye faydalı olacağı düşünülmektedir (Olkin, 1999; Simpson & Thomas, 2014).

1.4.Türkiye’de Engellilik Hareketi

Türkiye’de engellilik uzun bir süre boyunca bireysel modeller çerçevesinde anlaşılmaya çalışılmış; bu durum, ülkemizdeki yasal mevzuatın da sosyal bakış açısından uzak şekillenmesine neden olmuştur. Kısaca ifade etmek gerekirse, Türkiye’deki engellilik hareketinin gelişiminde, toplumsal, ekonomik ve politik faktörler rol oynamıştır. Geri dönüp bakıldığında, engelliliğin sosyal ve insan hakları temelli bir bakış açısıyla değerlendirilmesi konusunda gelişmeler olmasına rağmen, bu değişimin en alt düzeyden en üst düzeye kadar gerçekleşmesi ihtiyacı devam etmektedir. Bu, engellilerin, 5378 sayılı Engelliler Hakkında Kanun’da ve Türkiye’nin de taraf olduğu Birleşmiş Milletler Engelli Hakları Sözleşmesi’nde (UN, 2006) belirtilen insan hakları ve temel özgürlüklerinden tam olarak faydalanabilmelerinin tek yoludur.

2. Beden Görünümü Araştırmaları

“Beden algısı”, bedenin psikolojik deneyimine dair bilişsel, duygusal, davranışsal bileşenleri içeren çok yönlü bir kavramdır (Cash, 2004). Literatürde birçok açıdan incelenmiştir; ancak çalışmaların birçoğu beden ağırlığı doyumu üzerine yürütülmüştür. Bu nedenle, doğuştan veya sonradan edinilmiş fiziksel engellilik gibi, görünümde değişikliğe neden olan durumların incelenmesi önem arz etmektedir.

2.1. Beden Algısı ve Engellilik

Bu alanda yapılan çalışmalar, engellilerde beden algısının yalnızca beden görünümündeki farklılıklardan değil, aynı zamanda beden işlevselliği ve potansiyelindeki farklılıklardan da kaynaklandığını ve bağımlı ve yük olma hisleriyle ilişkili olduğunu göstermiştir (Smith, 1984; akt. Taleporos & McCabe, 2002; Cicmil & Eli, 2014). Bununla birlikte, ana akım medyada sıklıkla yer alan "mükemmel beden" kavramının ve engellilerin ana akım medyada temsil edilmemesinin, engelli bedenlere ilişkin olumsuz önyargıları beslediği düşünülmektedir (Dawn, 2014). Bu önyargıların içselleştirilmesi ise, engellilerin kendi bedenlerine ilişkin utanç ve değersizleştirme gibi olumsuz duygulara ve tutumlara sahip olmalarına neden olmaktadır (Galvin, 2005).

2.2. Bedene Dair Utanç ve Engellilik

Bedene dair utanç duygusunun kaynakları ve sonuçları birçok çalışmada araştırılmıştır. Örneğin, Bessenoff ve Snow (2006), algılanan kültürel normların ve kişisel ideallerin beden utancıyla ilişkili olduğunu bulmuştur. Araştırmacılar, kültürel olarak kabul edilmiş güzellik ve bağımsızlık normlarının içselleştirilmesinin de, engelliler arasında utanç duygusu ve değersizlik hislerine sebep olduğunu bulmuşlardır (Rumsey, 2002; Dewis, 1989; Yuen & Hanson, 2002). Özellikle bağımsız yaşam olanaklarına erişimi olmayan engellilerin, fiziksel ihtiyaçları ve bağımlılıklarıyla ilgili olarak daha fazla utanç duygusu ifade ettikleri ve bunun, fiziksel ihtiyaçlarını yetersizlik olarak görmeleriyle bağlantılı olduğu bulunmuştur (Galvin, 2005). Engellilik, aynı çalışmada sosyal statünün kaybıyla ilişkili bulunmuştur. Bu gibi duygular, engellilerin yaşamlarının birçok alanını olumsuz etkilemektedir.

2.3. Romantik İlişkiler, Cinsellik ve Engellilik

Engellilerin romantik ilişkileri ve cinselliği uzun bir süre boyunca tıbbi bir bakış açısıyla yalnızca kısıtlılıklar üzerinden incelenmiş ve engellilerin bireysel yaşantılarına yer vermemiş olmasına rağmen (Shakespeare, Gillespie-Sells, & Davies, 1996, pp. 1-4), son dönemde araştırmalar engellilerin sağlıklı ve keyifli bir cinsel yaşama sahip olmasının önündeki bariyerleri anlamaya odaklanmıştır (Campbell, 2017). Bu bağlamda, özellikle toplumda var olan ve engellilerin cinsel yaşamlarıyla ilgili mitler ve tabuların, fiziksel kısıtlılıklardan daha olumsuz etkisinin olduğu bulunmuştur (Berman ve ark., 1999) . Bu durum, engellilerin cinselliği keşfetme ve ifade etmelerine engel olmakta ve hayatlarının birçok alanında ayrımcılığa ve dışlanmaya maruz kalmalarına yol açmaktadır. Örneğin, engellilerin kendi fiziksel durumlarıyla uyumlu bir cinsel eğitim alamadıkları (Bernard-Brak, Schmidt, Chesnut, Wei & Richman, 2014), cinsel sağlık ve üreme sağlığı hizmetlerine erişimde sıkıntılar yaşadıkları ve var olan önyargılar nedeniyle uzman desteği alamadıkları (Nguyen, Liamputtong, & Monfries) ifade edilmiştir. Bu durum da, engellilerin cinsel tacize ve cinsel yolla bulaşan hastalıklara açık hale gelmesine neden olmaktadır (Manoj & Suja, 2017).

Bunun yanında, cinselliğin doyum verici şekilde yaşanmasına engel olan fiziksel ve toplumsal etmenlerin, engellilerin psikolojik iyilik halleri üzerindeki etkisine odaklanan araştırmalar, bu etkinin kişinin engeline atfettiği anlama göre değişiklik gösterdiğini bulmuştur (Taleporos & McCabe, 2001; Kattari & Turner, 2017). Aynı şekilde, son zamanlarda engellilik alanında tartışılmaya başlanan konulardan bir tanesi de cinsel zevk ve doyumdur. Tepper (2000)'e göre, cinsellikten alınan zevk insanlara canlı hissettirdiği, fiziksel ve duygusal acılarla baş edilmesine yardımcı olduğu ve dünyayla ve diğer insanlarla bağlılık hissini güçlendirdiğinden dolayı herkes için oldukça önemlidir. Ayrıca, engelliler için cinsel doyumun konuşulması, yalnızca mükemmel bedenlere sahip kişilerin cinsel doyum ve zevki hak ettiğine dair mesajlara karşı koruyucu bir işlevi vardır. Aynı zamanda, engellilik ve cinsellik çalışmaları, cinsel doyumun cinsel birleşme dışında farklı yollarla alınabileceğini ve cinselliğin ve zevk kaynaklarının kişiden kişiye değiştiğini göstermiştir.

2.4. Benlik Kavramı ve Engellilik

Beden algısı, benlik kavramı ve engellilik alanındaki çalışmalar, engellilerin beden görünümleri ve işlevselliklerine bağlı olarak gelişen benliklerine dair çelişkili sonuçlar sunmaktadır. Ancak, bu çalışmaların birçoğunun özgüvene odaklandığı ve engellilik kimliği gibi boyutları göz ardı ettiği görülmektedir (Bogart, 2014). Bu nedenle, engellilik kimliği ve gururun ayrıntılı bir şekilde tartışılması gerekmektedir.

2.4.1. Engelli Kimliği ve Gurur

Engelli hakları çerçevesinden değerlendirilecek olursa, engelli kimliğinin kaynağı, benzer önyargı ve ayrımcılık deneyimleri olan bir engelli azınlık grubuna üyeliktir (Dunn & Burcaw, 2013). Bununla birlikte, bu kimliğin olumlu bir şekilde sahiplenilmesinin mümkün olduğu; böylece bireylerin, kendi engellilik durumlarını, kimliklerinin önemli ve değerli bir parçası olarak görebildikleri ve kimlikleriyle gurur duyabildikleri ifade edilmiştir (Nario-Redmond, Noel & Fern, 2013). Toplumda var olan engelleyici sistemle mücadelenin de, engelliliğin bir kişisel trajediden çok sarsılması gereken toplumsal yapının sonucu olduğunun anlaşılmasıyla başladığı vurgulanmıştır (Galvin, 2005).

Engellilik gururu, engelli bireylerin, engelliliğin bireysel yetersizlikler olduğu ve engellilerin diğer insanlardan daha aşağıda bir konuma sahip olduğu fikrine karşı çıkmaktadır (Darling & Heckert, 2010), ancak Türkiye gibi sağlamcı normların yaygın olduğu toplumlarda bu bakış açısının oluşmasının zor olduğu vurgulanmaktadır.

2.5. Türkiye'de Engellilik, Beden Algısı, Cinsellik ve Benlik Kavramı Araştırmaları

Türkiye'de beden algısı, cinsellik, benlik gelişimi ve kimlik gibi kavramlar engelli örneklemiyle çok az çalışılmıştır ve var olan az sayıdaki çalışma birbiriyle çelişkili bulgular sunmaktadır. Bununla birlikte, engellilik ve cinsellik alanındaki çalışmaların daha çok tıbbi model bakış açısıyla yürütüldüğü ve daha çok var olan fiziksel engellerin cinsel özgüven, cinsel davranışlar ve cinsel zevk üzerindeki etkisine odaklandığı görülmektedir (bkz. Akkuş & Duru, 2011; Altuntug, Ege, Akın, Kal & Sallı, 2014; Çelik ve ark., 2013). Ayrıca, bu çalışmaların hiçbiri, fiziksel engelli bireylerin öznel yaşantılarının anlaşılmasına odaklanmamıştır.

3. Çalışmanın Amacı

Bu çalışma, Türkiye'de, engellilik, beden algısı, cinsellik ve engelli kimliği oluşumuna dair çalışmaların yeterli sayıda bulunmaması nedeniyle tasarlanmış ve Türk fiziksel engelli bireylerin beden görünümleri ve işlevselliklerine dair benlik gelişimlerinin anlaşılmasını amaçlamıştır. Bu bağlamda, özellikle engelli bireylerin romantik ilişkileri ve cinsellik deneyimleri araştırılmıştır.

4. Araştırma Sorusu

Engellilerin beden görünümü ve işlevselliklerine dair deneyimleri, kendileriyle ve başkalarıyla olan ilişkilerini, özellikle romantik ilişkilerini ve cinselliği nasıl etkilemektedir?

BÖLÜM II: YÖNTEM

1. Metodoloji

Literatüre bakıldığında, fiziksel engelliliğin psikolojik etkilerine dair çalışmaların genellikle nicel yöntemlerle yürütüldüğü görülmektedir. Oysa engelliliği, bunu bireysel olarak deneyimleyenlerin bakış açısıyla anlamlandırmak önemlidir. Bu nedenle, bu çalışmanın nitel olarak yürütülmesi ve temellendirilmiş kuram metodolojisinin kullanılmasına karar verilmiştir.

Temellendirilmiş kuram, Glaser ve Strauss (1967) tarafından geliştirilmiş ve bireylerin, diğerleriyle olan sosyal etkileşimlerini ve bu etkileşimlerin anlamlarını ortaya çıktıkları bağlamda anlamayı amaçlayan nitel bir metodolojidir. Bu çalışmada, birçok yaklaşım arasından yapısalcı yaklaşım tercih edilmiştir. Yapısalcı yaklaşım, nesnel bir gerçekliğin olmadığını, aksine gerçekliğin sosyal etkişimler yoluyla inşa edildiğini vurgulamaktadır (Charmaz, 2008). Bu bağlamda, araştırmacının süreç boyunca kendi rolünü değerlendirmesi önem arz etmektedir (Charmaz, 2006, pp. 129-131). Bu çalışmada, temellendirilmiş kuramın seçilme nedeni ise, bu metodolojinin araştırmacıya Türkiye'de tekerlekli sandalye kullanan fiziksel engelli bireylerin psikolojik ve sosyal deneyimlerine dair açıklayıcı bir kuram geliştirme imkânı sağlamış olmasıdır.

2. Katılımcılar ve Örnekleme Yöntemi

Bu çalışma, kuramsal örnekleme yöntemiyle, yani elde edilen verilerin analizine göre, bir kuramın geliştirilebilmesi için gerekli olduğu düşünülen özellikteki katılımcıların çalışmaya dâhil edilmesi yoluyla yürütülmüştür (Glaser & Strauss, 1967). Çalışmaya 5 kadın 5 erkek olmak üzere, toplamda 10 fiziksel engelli tekerlekli sandalye kullanıcısı birey katılmıştır. Çalışmanın özellikleri göz önünde bulundurulduğunda, katılımcı sayısının, tipik temellendirilmiş kuram çalışmalarıyla benzerlik gösterdiği düşünülmüştür (Morse, 2000; Starks & Brown Trinidad, 2007).

3. İşlem

Çalışmanın etik izni Orta Doğu Teknik Üniversitesi İnsan Araştırmaları Etik Komitesi'nden alınmıştır (No: 2015-SOS-170). Görüşmelere, katılımcıların yazılı ve sözlü onamları alındıktan sonra başlanmıştır. Her katılımcıyla yarı-yapılandırılmış görüşmeler yapılmış; görüşmeler katılımcıların beden görünümleri ve işlevselliğine dair kendi gündemlerine göre şekillenmiştir. Görüşmeler kayıt altına alınmış ve analiz için araştırmacı tarafından yazıya dökülmüştür. Katılımcıların gizliliğinin sağlanabilmesi açısından, kimlik belirleyici bazı bilgiler görüşmelerin yazıya dökülmesi ve sonuçların raporlanması esnasında değiştirilmiştir.

4. Verilerin Analizi

Analiz sürecinde, Charmaz (2006)'ın temellendirilmiş kuram metodolojisi için önermiş olduğu gibi, veriler öncelikle satır satır kodlanmıştır. Daha sonra, bu kodlar anlamlı kategorilere sınıflandırılmıştır. Sürekli kıyas metoduyla ise, katılımcıların kendi içlerinde ve diğerleriyle aralarındaki benzerlikler ve farklılıkların bulunması amaçlanmıştır. Bu sürece paralel olarak, ortaya çıkan kategorilerin daha iyi anlamlandırılabilmesi ve araştırmacının kendi rolünü gözlemleyebilmesi açısından memolar tutulmuştur. Bu süreç, her katılımcıyla yapılan görüşme sonunda tekrarlanmıştır. Elde edilen veriler, MaxQDA programı yardımıyla analiz edilmiştir (Verbi Software, 2005).

5. Çalışmanın Güvenilirliği

Nitel çalışmaların güvenirliliğini arttırmak için çeşitli yöntemler bulunmaktadır (Smith, 1996). Literatürdeki öneriler dikkate alınarak, mevcut çalışmayı yürüten araştırmacı, analizin tutarlı ve bütünlüklü bir şekilde yürütülmesine önem göstermiştir. Bunun yanında, araştırmacı, elde edilen sonuçları nitel analiz konusunda deneyimli psikologlar, engellilik alanında çalışan aktivistler ve çalışmanın iki katılımcısıyla paylaşmış ve onlarla yaptığı tarışmalar sonucunda geliştirdiği kuramı gözden geçirmiştir. Bütün bu süreç aynı zamanda çalışmanın süpervizörü ve tez izleme komitesi tarafından izlenmiştir. Araştırmacı, bulguları raporlarken, analizin inanırlığını arttırmak amacıyla geliştirilen kuramın parçalarına dair görüşmelerden örnekler sunmuştur. Son olarak, araştırmacı, sürece dair kendi duygu ve düşüncelerini anlamlandırabilmek açısından memolar tutmuştur.

6. Kendini Yansıtma

Engelli bir birey olarak kendi kişisel deneyimlerim, psikoloji alanındaki eğitimim, klinik psikolog olarak mesleki deneyimlerim ve engellilik araştırmaları ve engelli hakları aktivizmi alanına ilgim, araştırma sürecini başından sonuna kadar etkilemiştir. Bununla birlikte, tez süpervizörüm tüm süreci izlemiş ve deneyimli bir klinik psikolog olarak, ayrışma bireyleşme sürecine dair düşüncelerimi şekillendirmeme ve sürece dair duygularımı anlamlandırmama yardımcı olmuştur. Genel olarak, bu çalışma klinik psikoloji ve engellilik çalışmaları alanlarında bilgi ve deneyim kazanmamı, görünüşte ayrı olan bu iki alanı birleştirmemi, fiziksel engelli bireylerin içsel yaşamlarını daha iyi anlamamı ve kendi hayatımda bağımsızlık arayışına devam etmemi sağlamıştır.

BÖLÜM III: BULGULAR

Engellilik deneyimi, fiziksel sakatlıklar ve toplumsal engellerin varlığıyla başlamaktadır (Kategori #1). İkisinin arasındaki etkileşim, toplumda var olan idealist ve sağlamcı normların engelliler tarafından içselleştirilmesine (Kategori #2) ve engellilerin kendi bedenlerini garip (#2a), bağımlı (#2b) ve yük (#2c) olarak algılamasına neden olmaktadır. Bu bakış açısına sahip engelliler için, problemin kaynağı bedenlerinin görünümündeki ve işlevselliğindeki farklılık olduğu için, normalliği arzulamaya (Kategori #3) başlarlar. Bunun sonucunda, toplumda var olan engeller ve buna bağlı olarak ortaya çıkan normların içselleştirilmesi artmaktadır. Öte yandan, toplumdaki normların sorgulanması engellilerin ayrı bireyler olarak kendilerini kabul edebilmesini sağlamakta (Kategori #4) ve böylece kendi otantik benliklerine ulaşabilmektedirler (Kategori #5). Bu bulgular, dışlanma ve utanç veya dahil olma ve gururla olan ilişkileri üzerinden tartışılacaktır.

1. Kategori #1: Fiziksel sakatlıkların ve toplumsal engellerin etkileşimi

Engellilik deneyimi, fiziksel sakatlığın varlığıyla başlamaktadır. Fiziksel sakatlıklar, bedende bazı işlevlerin kaybıyla ilişkilidir. Bu işlev kayıpları, engellilerin bazı gündelik aktivitelerde başkalarının yardımına ihtiyaç duymasına neden olmaktadır. Engellilik durumunun başlangıcındaki farklılıklar, bu işlev kayıplarının nasıl algılandığını etkilemektedir. Doğuştan engelli bireylerde, fiziksel kısıtlılıkların varlığı ve başkalarına duyulan ihtiyaç kendilik algısıyla bütünleşmiş olabilirken, sonradan engelli olan bireyler, yeni bir gerçekliğe uyum sağlamak durumunda kalmaktadırlar. Ayrıca, engelli bireyler, fiziksel durumlarını korumak ya da iyileştirmek adına birçok tıbbi müdahale ve tedaviden geçmek durumundadırlar. Buna verilen anlam da kişiden kişiye göre değişmektedir. Örneğin, bazıları için bu tedaviler onlara yardımcı bir işlemken bazıları için kendilerini normalden farklı hissetmelerine neden olan bir süreçtir.

Toplumsal engellerin varlığı, katılımcıların tümü tarafından paylaşılan ve onların topluma dahil olmasına engel olan bir durumdur. Toplumsal engeller, erişilebilirliğin sağlanamaması gibi fiziksel bariyerlerden ya da toplumdaki diğer bireylerin engellilere yönelik olumsuz tutumlarından oluşmaktadır. Bu tutumlar, Türkiye'de engellilik meselelerine yönelik farkındalığın düşük olduğunu ve engelliliğin kişisel bir trajedi olarak görüldüğünü göstermektedir çünkü insanların birçoğu engellilerin yaşamlarının bedenlerindeki sakatlıklar nedeniyle kısıtlandığını düşünmektedir. Bu durum, toplumdaki engelli olan ve olmayan herkesin idealist ve sağlamcı mesajlara maruz kalmasına ve sonucunda ise, engellilerin bu mesajları içselleştirmelerine neden olmaktadır.

2. Kategori #2: Normların İçselleştirilmesi

Toplumda var olan idealist ve sağlamcı normlar, engellilerin, engelliliği benliklerinin bir parçası olarak algılamasını olumsuz şekilde etkilemektedir. Örneğin, bu normların içselleştirilmesi, sonradan engelli olan bir birey için, engelliliğin işlev kaybından fazlası olduğunu hissettirebilmektedir. Bu durumda, cinsiyet rollerinin etkili olduğu görülmüştür. Erkekler daha çok engellilikleri nedeniyle almaları gereken yönetici rolünü alamadıklarından, kadınlar ise kendilerini güzel ve çekici bulmakta zorlandıklarından bahsetmişlerdir. Bu deneyimler, engellilerde aşağılık hislerine neden olmakta ve engelliliğin kişisel bir trajedi olduğu algısını güçlendirmektedir. Bu da engelliliğe yönelik yardım anlayışının devamını sağlamakta ve engellilerin, diğer insanlarla farklı türde ilişkiler kurabilmesine engel olmaktadır. Sağlamcılığın asıl hedefi, engellilerin bedenidir; bu nedenle, idealist ve sağlamcı normların içselleştirilmesi, engellilerin bedenlerine dair algılarını olumsuz etkilemektedir. Bunun sonucunda, engelliler bedenlerini garip, bağımlı ve yük olarak görmekte ve böylece romantik ilişki ve cinsellik deneyimleri olumsuz etkilenmektedir.

2.1."... çünkü garip bir bedenim var"

Doğuştan veya sonradan olan fiziksel engellere sahip olan bazı katılımcılar, kendilerine yabancılar tarafından durmadan bakıldığını ve bunun da kendilerini farklı hissetmelerine sebep olduğunu anlatmışlardır. Bu hisler, ana akım medya ve kültürde engellilerin yer bulamamasıyla güçlenmektedir. Bu durum, engellilerin kendilerini topluma ait hissetmelerinin önünde bir engel teşkil etmektedir. Kendi bedenlerine ait olumsuz değerlendirmelerin sonucunda, engelliler belli tür kıyafetleri tercih edebilmekte ya da kıyafetlerini bedenlerindeki farklılıkları gizlemek için kullanabilmektedirler. Aynı şekilde, katılımcılar, toplumdaki diğer kişilerin onlara eş olarak diğer engelli kişileri uygun gördüğünü ve bu durumun, kendilerinin toplumda engeli olmayan diğer kişilerle eşit görülmediğinden kaynaklandığını düşünmektedirler. Bunun içselleştirilmesinin, engellilerin kişilerarası ilişkilerini olumsuz etkilediği ve bazılarının toplumun beklentilerine göre davranmaya başladığı görülmektedir.

2.2.“... çünkü bağımlı bir bedenim var”

Fiziksel bağımlılık, bazı engelliler için bağımlılığa dair olumsuz değerlendirmelerle birleştiğinde, birilerinin yardımına ihtiyaç duymaktan fazlası anlamına gelmektedir. Bu durum, nesnel bağımlılık düzeyinden ziyade, kişinin bağımlılık durumuna verdiği anlama göre değişmektedir. Bazı kişiler, kendilerini yük olarak görmekte, bazıları hayatlarını kontrol edemediklerini hissetmektedir. Bu durum aynı zamanda, toplumun bağımsız hareket edebilme becerisini yüceltmesiyle de ilişkili bulunmuştur. Bu yüceltme, engellilerin acınası ve bakıma muhtaç bireyler olarak görülmelerine neden olan etmenlerden bir tanesidir ve engellilerin kendilerine yönelik değerlendirmelerini olumsuz etkilemektedir. Engelliler de bağımlılığı bir zayıflık ya da sosyal statü kaybı olarak görebilmektedirler.

Bağımlılık aynı zamanda romantik ilişkiler ve cinselliğin önündeki bir engel olarak algılanmaktadır. Aileye fiziksel olarak bağımlı olmak, partnerlerle buluşmayı zorlaştırabilmektedir. Bu nedenle, bağımsız hareket edebilme, ilişkilerin sürdürülmesini sağlayan bir faktör olarak ifade edilmektedir. İkinci olarak, bağımlılığın bazı engelliler için başkalarına yük olma anlamına gelmesi de romantik ilişkileri ve cinselliği olumsuz etkilemektedir. Son olarak, normların içselleştirilmesinin sonucunda, fiziksel engellerin varlığı da engellilerin romantik ilişkiler ve cinsellik yaşayamayacaklarına inanmalarına sebep olan bir durum haline gelmektedir.

Bağımlılık aynı zamanda, engellilerin yaşama koşullarına dair sistematik düzenlemelerin var olmamasından dolayı, bireylerin ailelerinden ayrışamamalarına neden olmaktadır. Sürekli olarak aileden ya da partnerlerden destek almak, engelli bireylerin özgürlüklerini kısıtlamaktadır. Ancak, kişilerin kendi çevresi dışında birinden yardım alma fikrini çok olumlu değerlendirmedikleri dikkat çekmiştir.

2.3.“... çünkü yük olan bir bedenim var”

Engelliliğin engelliler ve çevresindekiler tarafından yük olarak algılanması, engellilerin suçluluk gibi birçok olumsuz duyguyla baş etmek durumunda kalmasına neden olmaktadır. Bu durum, özellikle bakım veren kişilerin zorunluluktan bunu yaptıklarını düşündükleri zaman daha yoğun bir şekilde yaşanmakta ve engelliler, onlarla kimsenin yaşamak istemeyeceğini düşünmeye başlamaktadırlar. Bazı engelliler ise, bazı romantik ilişkilerinin kendilerinin engelliliği sebebiyle bitmesiyle, bu düşüncelerinin desteklenmiş olduğunu ve partnerlerine hak verdiklerini anlatmaktadırlar. Böyle bir durumda, engellilerin, engellilik deneyimini zorlaştıran sosyal koşulları sorgulamayı bırakarak, sorunun kaynağını kendi bedenlerinde gördükleri dikkat çekmiştir. Aynı zamanda, halen devam eden romantik bir ilişki içinde olan engelliler için de, partnerlerin bakım veren rolü aldığı dikkat çekmekte ve engelliler bu nedenle partnerlerine şükran duygusu hissetmektedir. Ancak bu duygunun, aynı zamanda kendilerini daha aşağı bir konuma yerleştirmeleriyle alakalı olduğu da anlaşılmaktadır.

3. Kategori #3: Normalliğin Arzulanması

Toplumda varolan fiziksel ve tutumsal engeller, toplumdan alınan mesajların belirttiği gibi, engellilerin de sorunu kendi beden görünümleri ve işlevselliklerinde bulmalarına ve normalliği arzulamalarına neden olmaktadır. Bu arzu, engellilerin kendi gerçekliklerinden uzaklaşmalarına ve engellilikle ilişkili problemlerini dikkate almamalarına yol açmaktadır. Bunun yanında, bazı engelli bireylerin sormakta olduğu “ya engelli olmasaydım?” sorusu da benzer duyguları tetiklemektedir. Bu soruya verilen cevaplar, katılımcıların, engelliliğin hayatları üzerinde ne kadar olumsuz bir etkisinin olduğunu düşündüklerini göstermektedir.

Bu nedenden ötürü, olası tedaviler umutla beklenmektedir. Tedavilerin olumlu sonuçlanmasının beklenmesi doğalken, bu tedavilerin, topluma dahil olma sorununa tek çözüm olarak düşünülmesi engellilik deneyimini zorlaştırmaktadır. Normal olma beklentisi arttıkça, engelli bireylerin var olan sağlamcı sistemi zorlamaları imkânsızlaşmaktadır.

4. Kategori #4: Ayrı Bir Birey Olma

Engelli bireyler, içselleştirmiş oldukları normları sorgulayabildikleri bazı deneyimlerden bahsetmektedirler. Bu süreç, öncelikle toplumda var olan fiziksel ve tutumsal engellerin ortadan kalkmasıyla mümkün olmaktadır. Toplumun engellilerin ihtiyaçlarına göre ayarlaması, engellilerin kendilerini diğer herkes gibi hissedebilmesini sağlamaktadır. Bunun dışında, başkalarına bağımlılığı azaltacak yardımcı cihazların ve personelin, bunlara dair olumsuz yargıların üstesinden gelinerek kullanılmaya başlanması önemlidir; çünkü bunlar, bağımlılığı işaret eder gibi görünse de bağımsızlığın kazanılmasına destek olmaktadırlar. Bu durum, engellilerin özgüvenlerini kazanmalarına ve daha sağlam arkadaşlıklar ve romantik ilişkiler kurmalarına katkıda bulunmaktadır. İkinci olarak, aileyle veya arkadaşlarla destekleyici ilişkilerin kurulması da toplumdaki normların sorgulanmasını kolaylaştırmaktır. Burada önemli olan, ilişkilerin gerçekten de engelli bireylerin psikolojik büyümelerine yardımcı olacak nitelikte olmasıdır. Örneğin, engelli bireyler ailelerinin aşırı koruyucu ve müdahaleci tutumlarının destekleyici olmadığını ve bağımlılık hislerini arttırdığını anlatmaktadırlar. Son olarak, aile dışında, bağımsızlığı destekleyen kişilerin olması da bu süreci kolaylaştırmaktadır. Ayrıca, diğer engelli bireylerle kurulan arkadaşlıklar da, engellilerin kendilerine bakış açılarını değiştirerek ya da günlük problemlerine farklı çözüm yolları bulmasını sağlayarak onları güçlendirebilmektedir.

Bulgular, engellilerin bedenlerinin görünümü ve işlevselliğine dair içselleştirilmiş normların evli katılımcılarda daha mümkün olduğunu göstermiştir. Bu katılımcılar, toplumdaki önyargılara karşı çıkan partnerlerinin kendi istekleriyle onlarla birlikte olduğunu düşünmektedir. Bu sayede, katılımcıların ailelerinden ayrışmalarının kolaylaştığı ve toplumun beklentilerinden ayrı bir hayatın mümkün olduğuna inanabildikleri bulunmuştur. Ayrıca, kendilerine sunulan yardımları büyümek için kullanabildikleri anlaşılmaktadır.

5. Kategori #5: Otantiklik

Engelli bireylerin, bu süreç sonucunda, engellerini bir eksiklik değil, çeşitli var oluş biçimlerinden bir tanesi olarak gördükleri anlaşılmıştır. Görünüm açısından, fiziksel sakatlıklarını bir reddedilme nedeni olarak görmemeye ve kendilerini seksi ve çekici bulmaya başlamaktadırlar. Dolayısıyla, kendilerini toplumdan ve toplumsal güzellik standartlarından bağımsız değerlendirebilmektedirler. Bu sayede, romantik ilişkiler ve cinsellik konusunda da geleceğe dair daha umutlu konuşabilmektedirler. İşlevsellik açısından da, toplumda var olan normların sorgulanması, engellilerin kendi fiziksel gerçekliklerini, bireysel ihtiyaçlarını ve ilişkilerdeki rollerini kabul edebilmelerini sağlamaktadır. Bu kabullenme ile birlikte, engelli bireyler kendileriyle daha az çatışma haline girmektedirler. Aynı zamanda, engelliler yaşamlarını diğer bireyler gibi sürdürmenin yolunu bulduklarında, topluma dahil olabilmek için kendi bedenlerini değiştirme arzusundan vazgeçebilmektedirler. Böylece, kendilerini kabul edebilir ve kısıtlı işlevselliklerine dair olumsuz değerlendirmeleri içselleştirmemeyi başarabilir hale gelmektedirler.

Engelliler, fiziksel gerçekliklerini kabul edebilir hale geldikçe, kendi bağımsızlıklarını arttıracak çözümleri daha rahat bulabilmektedirler. Dolayısıyla, engelliliğe ve yardımcı cihazlara dair olumsuz değerlendirmeler içselleştirilmeden bireysel ihtiyaçların kabul edilmesi, engellilerin daha bağımsız olmasını ve topluma daha çok dahil olabilmelerini sağlamaktadırlar.

Son olarak, engelliler, kendi fiziksel durumlarına ilişkin kavramsallaştırmaları değiştikçe, başkalarıyla olan ilişkilerini de farklı bir bakış açısıyla değerlendirmektedirler. Bu yolla, bazı insanların bağımlılıklarından bağımsız bir şekilde kendileriyle birlikte olmak isteyebileceklerini fark etmekte ve bu pozitif deneyimlerin sonucunda kendilerini artık yük gibi hissetmemektedirler. Bu nedenle, kısıtlı işlevsellikleri daha az sorun yaratmakta çünkü başkalarına bağımlı olmayı, ilişkide daha düşük bir seviyede olmakla eşleştirmemektedirler. Bir diğer deyişle, biricik bir ilişkiye sahip olmak ancak, engellilerin kendi ihtiyaçlarını olduğu gibi kabul edebilmeleriyle mümkün olmaktadır. Ayrıca, engelliler, başkalarının yardımına olan bağımlılıklarını, bu yardımı kendi istedikleri doğrultusunda kullanabileceklerini fark ettiklerinde kabul edebilmektedirler. Ancak, bu kabul ile yardımı yalnızca tek bir kaynaktan temin etme ihtiyacını ayrıştırmak önemlidir çünkü bu durum bağımlılık hislerinin artmasına neden olabilmektedir.

Bu kabullenmenin sonucunda, bazı engelli bireyler, engellilerin sürekli olarak maruz kaldığı ayrımcılıkla mücadele etmeyi tercih edebilmektedirler. Bu durum, topluma dahil olmak için savaşmanın mümkün olduğunu, engelli bireylerin güçlenmesini sağladığını ve sağlamcı sistemin değişmesinde etkili olduğunu göstermektedir. Dolayısıyla, engelliler söz konusu olduğunda bahsedilen uyum, engellilerin topluma uyumundan ziyade, kendilerinin farklılıklarını kabul ederek fiziksel gerçekliklerine uyum sağlamalarını ve değişimi toplumdan beklemelerini içermektedir.

BÖLÜM IV: TARTIŞMA

1. Bulguların Tartışılması

1.1. İdealist ve Sağlamcı Normların İçselleştirilmesi

Bu çalışmanın temel bulgusu, engelli bireylerin, toplumdaki idealist ve sağlamcı normları içselleştirmesinin, fiziksel ve tutumsal bariyerlerle başlayan sağlamcı döngünün devamındaki önemli rolünü göstermektedir. Bu bulgu, engellilik deneyimde psikolojik ve sosyal faktörlerin etkileşimini vurgulamaktadır.

Engelli bireylerde, beden ideallerinin içselleştirilmesinin utanca yol açtığı bulgusu görünümle ilgili yapılan ve beden ideallerinin ergenlerde ve yetişkinlerde görünüme dair memnuniyetsizlik hislerine yol açtığını gösteren araştırmalarla tutarlılık göstermektedir (Clark & Tiggemann, 2008; Myers & Crowther, 2009; Fitzsimmons-Craft; 2012; Arroyo, 2015; Trekels & Eggermont, 2017). Bu çalışmalar, ana akım medya ve sosyal kıyaslamanın etkisini vurgulamaktadır. Engelliler açısından bakıldığında, engellilerin olumlu temsilinin kısıtlı olmasından dolayı, bu etkinin daha yüksek olduğu ifade edilmektedir. Barnes (1991,1992) engelli bireylerin genelde cinsellikten uzak ve çekici bulunmayan olarak resmedildiğini ifade etmektedir. Bu tarz yanlış temsiller yalnızca engelli olmayan bireylerin engellilikle ilgili algılarını etkilemekle kalmayıp aynı zamanda engellilerin kendilerine dair algılarını da içselleştirmeler yoluyla etkilemektedir. Bu çalışmanın bulguları, Türkiye'de yaşayan engelli bireylerin de mükemmel bedeni yücelten mesajlara maruz kaldığını ve bedenlerindeki farklılıkları, romantik ilişkiler ve cinsellikte reddedilmelerinin bir nedeni olarak gördüklerini göstermektedir. Aynı zamanda, partnerleriyle kendi kişisel deneyimleri de bu görüşü destekleyecek şekilde sonuçlanmıştır.

Toplumdaki normların içselleştirilmesinin utanç duygularıyla ilişkili olduğu bulgusu da sağlamcılık ve içselleştirilmiş sağlamcılığın etkisini inceleyen diğer çalışmalarla tutarlı bulunmuştur. Bu çalışmalara göre, sağlamcı toplumlarda, engellilik utanç verici ve toplumda bir değere sahip olmak için kaçınılacak bir deneyim olarak algılanmaktadır (Overall, 2006). Bulgular, Türkiye'de engelli bireylerin acınacak ve yardıma muhtaç olarak algılandığını göstermektedir. Bu durum, Türk toplumunun temel olarak kolektivist değerlerin ve dinin etkisi altındaki sosyal yapısıyla (Cukur, Guzman, & Carlo, 2004) tutarlılık göstermektedir. Ayrıca, Kara (2007) Türk toplumunda ataerkil özelliklerin çok yaygın olduğunu vurgulamıştır. Bunlar, toplumun engelliliğe bireysel bir trajedi olarak yaklaşmasını açıklayan etmenlerden olabilir. Öte yandan, bu çalışmanın bulguları, toplumdaki sağlamcı normların engellilerin hayatlarını birçok açıdan olumsuz etkilediğini göstermektedir. Fiziksel ve kurumsal engellerle birleştiğinde, bu normların varlığı engellilerin varoluşunu tehdit etmekte ve onların ekonomik, kültürel, sosyal ve duygusal yaşamlarını tehlikeye atmaktadır (Loje ve ark., 2013). Dolayısıyla, Türkiye'de olduğu gibi, yapısal ve sosyal açıdan engelli olmayan bireyler için düzenlenmiş sağlamcı bir toplumda, engellilerin sağlamcılığa karşı çıkması güçleşmekte ve bu normların içselleşmesine daha yatkın hale gelmektedirler. Bu da onların birbirinden uzaklaşmasına ve engellilik kültürü oluşturamamalarına neden olmaktadır (Campbell, 2001).

Engelli bireylerin bağımlılık ve yük olma hislerine dair normlar konusunda ise, en temel sorun, Türkiye'de engellilerin bağımsız yaşamalarını sağlayacak sosyal düzenlemelerin bulunmayışıdır. Bir sonraki bölümde ise bunun olası nedenleri tartışılacaktır.

1.2. Psikolojik Büyüme için Bağımsız Yaşam

Bu çalışmanın bulguları, Türkiye'de toplum içinde yaşayan fiziksel engellilerin çoğunlukla aileleri veya partnerleriyle yaşadıklarını göstermiş; yalnızca bir katılımcı kişisel asistanlık aldığından bahsetmiştir. Bunun sebeplerinden bir tanesi, böyle bir desteğin zayıflık olarak algılanmasıdır. Öte yandan, bunu sağlayacak bir sistemin olmayışı, böyle bir destek bulmayı ve kullanmayı imkansız hale getirmektedir. Batı'da yapılan araştırmalar, bağımsız yaşamı sağlayacak düzenlemelerin, engellilerin hayatlarında kontrol ve seçim olanağına sahip olmalarını sağladığını göstermiştir. Böyle bir düzenlemenin olmaması, engellilerin kendilerini başkalarına fiziksel ve ekonomik olarak yük olduklarını hissetmelerine (Schafer, 1995) ve ilişkilerinin zarar görmesine sebep olurken (Boström, Ahlström, & Sunvisson, 2006; Jumisko, Lexell, & Söderberg, 2007), bu haktan faydalanabilen engelli bireylerin psikolojik iyi olma hallerinin arttığı bulunmuştur (Stainton & Boyce, 2004; Nosek, Fuhrer & Potter, 1995).

Türkiye'nin geleneksel kolektivist değerlere sahip muhafazakar bir ülke olmasının engellilerin bağımsız yaşama dair bakış açısını etkilediği düşünülmektedir. Kolektivizm, engellilerin diğer aile üyelerinden destek almalarını desteklemekte ve yabancı birinden destek alma fikri aile için utanç verici bir durum haline gelmektedir. Ayrıca, dini inanışlar da, ihtiyacı olan kişiye yardım etme gerekliliğini savunmakta ve engellilik, engelli bireyin kendisinin ve çevresindeki herkesin geçmesi gereken ilahi bir sınav olarak algılanmaktadır. Bunun sonucunda, engelli birey aile ve toplum içinde sürekli yardıma muhtaç olan çocuksu bir konuma zorlanmaktadır. Oysa ki, birçok kişilik kuramı sağlıklı psikolojik gelişim için ayrışma ve bireyleşmenin önemini vurgulamaktadır. Örneğin, Erikson (1950, 1963), bu süreci, çocuğun artan hareketliliğinin bir sonucu olarak görmüş ve bu sürecin engellenmesinin, yetersizlik, başkalarına bağımlılık, utanç ve kendi becerilerine şüphe hislerine neden olduğunu açıklamıştır (akt. Feist & Feist, 2008). Bu sürecin, engelli çocuklarda, fiziksel sakatlıkların varlığıyla engellenebileceği gibi, ailelerin reddedici ya da aşırı koruyucu tutumlarıyla da engellenebileceği bulunmuştur (Mordock, 1979; Ozhek, 2007). Ayrışma-bireyleşme süreci, ergenlik ve yetişkinlikte de devam etmekte ve bireylerin kendi kimliklerini oluşturabilmeleri, sorumluluk alabilmeleri ve yetişkin ilişkiler kurabilmeleri beklenmektedir (Koepke & Denissen, 2012). Görüldüğü gibi, ayrışma-bireyleşme süreci, bağımsız yaşam hareketinin ilkeleriyle yakından ilişkilidir.

1.3.Dışlanma/Dahil Olma ve Utanç/Gurur

Bu çalışmanın bulguları, engelli bireylerinin hayatın farklı alanlarına katılımlarının kısıtlanmakta olduğunu göstermektedir. Toplumdan dışlanma, sağlamcı döngünün bir sonucu olduğu kadar, bu döngünün devamına da katkıda bulunmaktadır çünkü dışlanma, engellilerin güçlenmesine engel olmakta, içselleştirmelerinin devamını sağlamakta ve onları daha aşağı bir konumda kalmaya zorlamaktadır. Öte yandan, bulgular, topluma dahil olmanın engelli çocuk ve yetişkinlerin güçlenmesini sağladığını gösteren çalışmalarla tutarlılık göstermektedir (Hutzler, Fliess, Chacham & Van den Auweele, 2002; Burton, Sayrafi, & Srour, 2013). Bunun sonucunda, utanç duygularının yerini gururun aldığı gözlemlenmiştir. Böylece, hak temelli bir savunuculuk içine girebilmekte ve toplumsal engeller nedeniyle topluma tamamen dahil olmaları henüz mümkün olmasa da, gelecekten daha umutlu hissedebilmektedirler çünkü kendi bedenlerini değiştirmek yerine değişebilecek olanı, yani toplumu, değiştirmeye odaklanabilmektedirler.

2. Çalışmanın Katkıları

2.1. Pratik Katkıları

Bu çalışma, engellilerin topluma dahil olmasını engelleyen sosyal ve psikolojik etmenlerin etkileşimini ve Türkiye'de yapılmış diğer çalışmalarda olduğu gibi (Özbulut & Özgür Sayar, 2009; Özgökçeler & Bıçkı, 2010; Genç, 2015) fiziksel ve sosyal engellerin ortadan kaldırılmasının önemini göstermektedir. Ayrıca, idealist ve sağlamcı normların içselleştirilmesine dair ana bulgular, engellilerin güçlendirilmesinin önemini vurgulamaktadır. Dolayısıyla, engellilerin temel hak ve özgürlüklerine yönelik bilgilerin hem engelli hem de engelli olmayan bireylere sağlanması gerekmektedir. Toplumda var olan idealist ve sağlamcı normların yıkılması için, ana akım medyadaki engelli temsillerinin gözden geçirilmesi önerilmektedir. Bu müdahalelerin beden kabulünü sağlayarak, engelli bireylerin yanı sıra, engeli olmayan bireyler için de faydalı olacağı düşünülmektedir (McKinley, 2004; Swami, Weis, Barron, & Furnham, 2017).

Bu çalışma, aynı zamanda, Türkiye'deki engelli bireylerin bağımsız yaşam olanaklarına ihtiyacını göstermektedir. Bağımsız yaşamın temel bir hak olarak görülmemesi ve engelli bireylerin aileleriyle ve partnerleriyle yaşamak zorunda bırakılmaları engelleyici etmenlerden bir tanesidir. Bağımsız yaşam olanaklarının hem engelliler hem de onların ailelerinin hayatlarında esneklik sağlayacağı ve her iki grup için de faydalı olacağı düşünülmektedir. Bu nedenle, bağımsız yaşama dair düzenlemelerin talep edilmesi ve bağımsız yaşamın Türkiye'nin sosyal güvenlik sistemine uygun bir şekilde nasıl uygulanabileceğinin tartışılması gerekmektedir.

Son olarak, bu çalışma gururu temel alan bir engelli kimliği gelişiminin önemini göstermektedir. Ancak bu şekilde engelli bireylerin, engelliliğe dair hak temelli bir bakış açısı geliştirmesi mümkün olmaktadır. Bu nedenle, Türkiye'de engellilerin kendilerinin yönettiği engelli derneklerine olan ihtiyaç halen devam etmektedir.

2.2. Klinik Katkıları

Bu çalışma, birbirinden uzak olarak görülen engellilik çalışmaları ve klinik psikoloji alanlarını bir araya getiren az sayıdaki çalışmadan bir tanesidir. Bu çalışmanın nitel doğası, fiziksel engellilik deneyimine dair zengin ve ayrıntılı bilgiler sunmaktadır. Ayrıca, bu çalışma, bağımsız yaşam anlayışının var olmamasının psikolojik etkilerini açıklamaktadır. Bütün bunlar düşünüldüğünde, engellilerin güçlendirilmesine yönelik müdahalelerin geliştirilmesinin önemli bir ihtiyaç olduğu ortaya çıkmaktadır. Bu müdahalelerin, toplumda var olan normların sorgulanmasına odaklanması gerekmektedir. Son olarak, bu çalışma, engelli bireylerde utanç ve gurur duygularının gelişimine açıklık getirmektedir.

Bu çalışmanın bulguları, alanda engelli bireylerle çalışan ve onlara bireysel ya da grup müdahalelerinde bulunan uzmanlar için yol gösterici niteliktedir. Bu uzmanların, öncelikle engelliliğe ve engelli bireylere dair kendi varsayımlarını sorgulamaları ve engelliliği kişisel ve sosyal etmenlerle ilişkili bir deneyim olarak algılamaları önerilmektedir. Ayrıca, terapi süreçlerinde engellilerin ayrışma-bireyleşme süreçleri değerlendirilmeli ve engellilerin topluma tam ve eşit katılımı için terapi süreçlerinin odak noktalarından biri olmalıdır. Bu amaçla, ayrışma-bireyleşme karşılıklı bir süreç olduğu için, engellilerin ailelerine ve partnerlerine yönelik müdahaleler de geliştirilmelidir. Son olarak, engellilerle yürütülen psikoterapinin amacı, normale uyum sağlamaları yerine, kendi otantik benliklerini bulmalarını sağlamak olmalıdır.

3. Çalışmanın Kısıtlılıkları

Çalışmanın katılımcılarla yalnızca bir görüşme yapılarak yürütülmesi, temellendirilmiş kuram çalışmalarında kullanılabilecek diğer kaynaklara başvurulmaması ve farklı özelliklerde katılımcıların çalışmaya dahil edilmemesi bu çalışmanın kısıtlılıklarını oluşturmaktadır. Ancak, bu konuda Türkiye’de yürütülmüş ilk çalışma için elde edilen nitel bilgiler yeterli bulunmuş; ortaya çıkan kuramın bahsedilen yöntemlerle geliştirilebileceği düşünülmüştür.

4. Gelecek Çalışmalar için Öneriler

Gelecek çalışmalarda, engellilik deneyiminin farklı gruplarda nasıl yaşantılandığının anlaşılması açısından benzer bir çalışmanın daha az fiziksel engelli ya da diğer engel gruplarıyla yapılması önerilmektedir. Ayrıca, ayrışma-bireyleşme sürecinin, engelli bireylerin aileleri tarafından nasıl algılandığı da önemli görülmektedir. Ayrıca, engelliler utanç ve gurur dışında, üzüntü, endişe, kaygı ve öfke gibi diğer duygularla da mücadele etmek durumunda kalabilmektedirler. Bu nedenle, engellilik deneyiminin daha iyi anlaşulması açısından bu duyguların engellilerin hayatlarındaki yerini inceleyen çalışmaların faydalı olacağı düşünülmektedir. Son olarak, Türkiye'deki engellilerin bağımsız yaşamı nasıl algıladığına dair bir çalışmanın yapılmasının, engellilerin ihtiyaçlarına uygun sistemlerin gelişmesini sağlayacağı düşünülmektedir.

5. Sonuçlar

Bu çalışma, engellilerin toplumdaki idealist ve sağlamcı normları içselleştirilmesinin ve sorgulanmasının, engellilerin kendi hayatları ve sağlamcı sistemler üzerindeki etkisini göstermiştir. Bu nedenle, engellilerin onurunu korumak ve topluma tam katılımlarını sağlamak için bireysel ve toplumsal düzlemde önlemlerin alınması önemlidir.