

ANALYSIS OF DAILY ACTIVITIES OF YOUNG PEOPLE
WITH CEREBRAL PALSY IN THEIR HOME
ENVIRONMENTS

A Master's Thesis

by
PINAR TANRIVERDİ

Department of
Interior Architecture and Environmental Design
İhsan Doğramacı Bilkent University
Ankara

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PINAR TANRIVERDİ

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PINAR TANRIVERDİ

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ABSTRACT

ANALYSIS OF DAILY ACTIVITIES OF YOUNG PEOPLE WITH CEREBRAL PALSY IN THEIR HOME ENVIRONMENTS

Tanrıverdi, Pınar

MFA, Department of Interior Architecture and Environmental Design

Supervisor: Assist. Prof. of Practice Dr. Burçak Altay

June 2022

In this study the difficulties experienced by young people with cerebral palsy, their level of dependence and related emotions and the level of importance they attach to daily living activities in the home environments are examined and compared. The main purpose of this study is to analyze which activities are most difficult for young people with cerebral palsy and the relationship between difficulties in activities and body parts. Also, it aims to examine during which activities young people with cerebral palsy are more dependent on others and how they feel as a result of this dependence. Furthermore, it also aims to compare the importance level that young people with cerebral palsy give to the activities. The survey phase is conducted with 31 young people with cerebral palsy aged 15-24. Afterwards, separate interviews are held with six participants who volunteered to take part in this phase, who also answered the survey questions. Survey results reveal that young people with cerebral

palsy experience varied levels of difficulty in different activities. Also, there is a relationship between difficulties in doing activities and difficulties they experience in different parts of their bodies. Moreover, difficulties in doing daily activities increased their dependence and different emotions occur because of this. Finally, the survey results show that the importance level that young people with cerebral palsy give to the daily activities shift. Interview results reveal that the reasons why young people with cerebral palsy cannot do or not do activities differ and these reasons are explained. Also, the emotions that occur because of being dependent on others and the adaptations that they made or want to make in their homes are discussed.

Keywords: Cerebral Palsy, Mobility Difficulties, Home Environment, Daily Living Activities, Dependence

ÖZET

SEREBRAL PALSİLİ GENÇLERİN EV ORTAMLARINDAKİ GÜNLÜK AKTİVİTELERİNİN ANALİZİ

Tanrıverdi, Pınar

Yüksek Lisans, İç Mimarlık ve Çevre Tasarımı Bölümü

Tez Danışmanı: Dr. Öğretim Üyesi Burçak Altay

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Bu çalışmada serebral palsili gençlerin günlük aktivitelerini yaparken yaşadıkları zorluklar, başkalarına bağımlılık seviyeleri ve buna bağlı oluşan duygular ve günlük aktivitelere verdikleri önem incelenmekte ve karşılaştırılmaktadır. Çalışmanın temel amacı, serebral palsili gençlerin hangi aktiviteleri yaparken daha çok zorlandığını analiz etmek ve bu zorluğun onların bedenlerinde yaşadıkları zorluklarla ilgisini anlamaktır. Ayrıca, serebral palsili gençlerin hangi günlük aktiviteleri yaparken başkalarına daha çok bağımlı olduğu ve bu bağımlılık sonucunda hissettiklerini incelemeyi amaçlamaktadır. Ek olarak, serebral palsili gençlerin etkinliklere verdikleri önem derecesini karşılaştırmak da hedeflenmektedir. Araştırmanın anket aşaması 15-24 yaşları arasında serebral palsili 31 genç ile gerçekleştirilmiştir. Ankete katılan katılımcılardan seçilen altı kişilik hedef grubu üyeleri ile ayrı röportajlar gerçekleştirilmiştir. Anket bulguları, serebral palsili gençlerin farklı aktivitelerde

zorluk seviyelerinin deęiřtięini gstermektedir. Ayrıca, serebral palsili gençlerin günlük aktivitelerini gerçekleştirirken yaşadıkları zorlukların bedenlerinde yaşadıkları zorluklarla ilişkili olduęu anlaşılmıştır. Ek olarak, günlük aktivitelerini yürütmekte zorluk yaşamalarının başkalarına baęımlılıklarını arttırdıęı ve bu baęımlılık nedeniyle farklı duygular ortaya çıktıęı belirlenmiştir. Son olarak bulgular, serebral palsili gençlerin günlük aktivitelere verdikleri önem düzeylerinin deęiřtięini gstermektedir. Röportaj bulguları, serebral palsili gençlerin aktiviteleri yapamama ve yapamama nedenlerinin farklılık gösterdięini ortaya koymakta ve bu nedenler açıklanmaktadır. Ayrıca, başkalarına baęımlı olma nedeniyle oluşan duygular ve evlerinde yaptıkları veya yapmak istedikleri deęişiklikler ele alınmıştır.

Anahtar kelimeler: Serebral Palsi, Hareketlilik Zorlukları, Ev Ortamı, Günlük Aktiviteler, Baęımlılık

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I'm not upset that it's over. You raised me, you made me, me. As everyone says, I am my mother's daughter, and thanks to you, all the roads i walk have your trace and light.

Rest in peace, you are always with us, I love you with all my heart.

Your little girl

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LIST OF ABBREVIATIONS

NCDD: Nationally Consistent Collection of Data

NDS: National Disability Services

CP: Cerebral Palsy

BADL: Basic Activities of Daily Living

IADL: Instrumental Activities of Daily Living

UPIAS: Union of the Physically Impaired Against Segregation

GMFCS: The Gross Motor Functional Classification System

WHO: World Health Organization

SERÇEV: Association of Children with Cerebral Palsy
(Serebral Palsili Çocuklar Derneği)

Q: Question

RQ: Research Question

H: Hypothesis

CHAPTER I

INTRODUCTION

Studying disability is a significant issue because of the high percentage of the population, but the studies in this area are still open to more research (Bolt, 2015).

TUIK (2011) stated that more than 500 million people in the world are disabled and this number is increasing. Therefore, the needs of disabled people should be given importance. Considering the needs of people with disabilities, it is important to design their living spaces in an accessible way so that they can meet their daily activities more effectively on their own.

According to National Disability Services (n.d.), there are different disability types including *intellectual, acquired brain injury, neurological, deafblind, vision, hearing, speech, psychiatric* and *physical disabilities*. Considering physical disability, it also has different types such as *paraplegia, quadriplegia, multiple sclerosis (MS), hemiplegia, absent limb/reduced limb function, dystrophy, polio* and *cerebral palsy* (National Educational Association of Disabled Students, n.d.). Among physical disability types, disabled people with muscle disorders such as people with cerebral palsy generally live mobility difficulties (Routhier et al., 2003). They can need supports as personal support, crutches or wheelchairs. In this study, the people who have mobility difficulties will be analyzed.

The needs of people with mobility difficulties should be taken into account and more accessible spaces should be designed to ensure both greater understanding and better

mobility for them in the living environment. As Bolt (2015) emphasized, although the importance of accessible design is known, it is a matter of debate whether the wishes and needs of people with mobility difficulties are given sufficient importance in terms of architecture. The needs of people with mobility difficulties are not a luxury, but a necessity for them to live and feel like everyone else. As Kelly et al. (2016) stated, when spaces are designed accessible, this not only increases the life quality of people who live mobility difficulties, but also improves their emotions and wellbeing.

When the spaces are inaccessible for people with mobility difficulties, it can create negative effects on their emotions. Sadness, guilt, and anger are some of these types of emotions (Imrie, 2004 & Kelly et al., 2016). As Perry (2009) emphasized, the areas designed in accordance with the needs of wheelchair users not only influence their emotions, but also help them to do their daily activities on their own because they move more comfortably. Besides, when people who have mobility difficulties can move in an environment without the help of others, their level of independence and self-esteem are strengthened (Agarwal and Pandey, 2013). Therefore, young people with disabilities should be understood and facilities should encourage them to feel more independent, and to overcome these difficulties without damage. In this study, being young disabled, the level of dependence and emerged emotions because of being dependent will be examined.

Accessibility in architecture has a significant role as houses are the most fundamental spaces for people to feel safe and independent. The arrangement of the spaces in the home environment should be aimed at enabling them to move more comfortably (Routhier et al., 2003). Therefore, the most effective accessibility level should be provided by considering the obstacles that people with mobility difficulties can

encounter. According to Cambridge Dictionary (n.d.), mobility is defined as “the ability to move freely or be easily moved”. There may be different barriers that people with mobility difficulties can face. For instance, as Imrie (2006) emphasized, having narrow spaces or high-rise furniture are some of the barriers that restrict the movement of people with mobility difficulties. In this study, the importance of mobility in home environments will be discussed.

There are different spaces in home environments such as entrances and circulation areas, living rooms, bedrooms, kitchens or bathrooms. Considering the possible obstacles that can be encountered by people with mobility difficulties, arrangements of the architectural elements including layout of the spaces or furniture should be taken into account. For instance, according to Norin et al. (2020), entrances are the spaces where environmental barriers are the most common. Entrances are followed by kitchens and bathrooms. The reasons for these barriers should be analyzed and solutions ought to be found. In this study, the most common obstacles in the homes for people with mobility difficulties and possible adaptations will be discussed.

There is no doubt that the accessibility conditions of the spaces should be suitable for people with mobility difficulties to carry out their daily activities and move freely in the environment (Fänge & Iwarsson, 2003). In order to design the spaces of the home environment, the daily activities of people should be examined in the first stage. As Boverket (2000) emphasized, it is significant to understand the activities of people to organize the environments in which they live, according to their needs. Since each individual is different, it is important to understand their wishes and the level of difficulty they experience in activities while creating suitable environments for them. In this study, the daily activities of people with mobility difficulties in their home

environments including the difficulties they experience in each space and the importance levels they give to the daily activities will be investigated.

1.1. Aim of the Study

The primary aim of this study is to investigate the lives of people with cerebral palsy who have different capabilities to enhance their life qualities by examining their daily activities. Particularly, the aim is to understand what young people with cerebral palsy experience while doing daily activities in the home environment. By exploring the daily activities, it is aimed to analyze the difficulty levels that they experience in doing daily activities, their level of dependence and related emotions and the importance levels that they give to the activities.

1.2. Structure of the Study

This thesis consists of seven chapters. In the first chapter, the introduction gives brief information about the thesis. The contents of the headings that are examined in the literature and the importance of the issues to be discussed are mentioned. Besides, the aim of the thesis is stated.

In the second chapter, the information obtained from the literature is discussed in more detail. To make the concept of disability more understandable, different points of view about disability are stated in addition to the definitions. The importance of addressing the concept of disability and some problems that disabled people can face in society are mentioned. After briefly mentioning the types of disability, the focus is given to cerebral palsy. Thus, to understand cerebral palsy better, its types and the ability differences are briefly mentioned. Also, the importance of mobility and being

young with mobility difficulties including their emotions about being dependent are discussed.

In the third chapter, the home environment is studied in detail. The importance of accessibility in homes and the concept of universal design are mentioned. In addition, the importance of increasing the mobility of wheelchair users and their experiences in the spaces of home environments when they encounter mobility difficulties are discussed. Then, the daily activities, including the difficulties people experience in these activities and the importance levels that they give to the daily activities are examined.

In the fourth chapter, the gaps in the literature and the importance of this study are mentioned. After considering the aim of the thesis and the information obtained from the literature, the research questions and hypotheses that emerged are mentioned. Furthermore, the study procedure, sampling procedure, setting of the study, instruments and the pilot study are explained in detail under the heading of methodology.

In the fifth chapter, the results of the survey are analyzed statistically. In addition, the results of the open-ended survey questions and interviews are analyzed by carrying out content analysis.

In the sixth chapter, the results obtained from the study are compared with other studies in the literature related to the daily activities of people who live mobility problems. Also, the possible reasons of the results are discussed.

In the seventh chapter, in the light of the information came as a result of the study, a conclusion is obtained. Moreover, some suggestions are made with regards to the interior architecture and issues that need to be addressed for designers are mentioned. Also, in this chapter, limitations of the study and future research areas are explained.

CHAPTER II

DISABILITY

Disability is an important issue considering the number of people with disabilities and the difficulties they experience. According to TUIK (2011), more than 500 million people in the world are disabled and they represent 10% of the total population. There are many different definitions of the term disability. According to WHO (2011), “Disability is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual and that individual’s contextual factors” (p.4). Disabled is also defined as an individual who has become physically or mentally incompetent due to congenital or acquired reasons (Akpınar and Şahin, 2016). Over the years, the definition of disability has been viewed from different perspectives so various definitions have occurred (Soyupak, 2021). It is pointed out by Union of the Physically Impaired Against Segregation (UPIAS) that in 1974, people with disabilities are excluded and exposed to pressure from the environment (Barnes, 2011). However, as the years passed, with the increased interest in being disabled and learning more about being disabled, the perspective on the concept of disability developed and changed (Bolt, 2015).

As can be realized, disability is often paired with a state of deficiency or inability. However, in fact, people with disabilities should not be seen as different from others. The research of WHO (2011) indicated that many disabled people do not see themselves as unhealthy and do not want to be thought of as unhealthy. For instance,

“40% of people with severe or profound disability who responded to the 2007–2008 Australian National Health Survey rated their health as good, very good, or excellent” (WHO, 2011, p.8). Besides, being seen as unhealthy is unfortunately not the only source of issues for them. Thus, they may face negative reactions such as having biased thoughts towards them, discrimination or bullying (WHO, 2011). Also, low incomes are one of the challenges that adult disabled people often face (Zhao et al., 2019). Therefore, besides providing them accessible spaces, the approach of the society for their feelings is also very crucial.

2.1. Disability Types

Disability is divided into different categories by variety of sources. According to Nationally Consistent Collection of Data (NCDD, n.d.), disability can be divided into the groups of *cognitive, sensory and social/emotional* and *physical*. Compared to other category systems, this may be the most compact categorization. National Disability Services (NDS, n.d.) also made another categorization for disability that is *intellectual, acquired brain injury, neurological, deafblind, vision, hearing, speech, psychiatric* and *physical*.

Intellectual disability is the state of having mental damage and experiencing mental adjustment problems (Lee & Marwaha, 2019). People with intellectual disabilities have neurological damage in their brains that occurs before the age of 18 (Shree & Shukla, 2016). Individuals who have an intellectual disability may experience problems in understanding logical and abstract concepts, solving problems and learning (Shree & Shukla, 2016). Lee & Marwaha (2019) stated that intellectual disability may happen because of mental damage including depression and anxiety, neurodevelopmental damage including autism spectrum disorders, attention deficit

and hyperactivity disorder, neurological damage including infantile cerebral palsy and medical causes such as meningitis. According to Shree & Shukla (2016), intellectual disability can emerge because of “chromosomal abnormalities such as down syndrome and fragile x syndrome, metabolic disorders such as phenylketonuria (PKU), maternal infections such as rubella (German measles), environmental conditions such as fetal alcohol syndrome, gestational disorders such as low birth weight/ prematurity, neonatal complications such as anoxia (oxygen deprivation), birth trauma, infectious and intoxicants such as meningitis and lead poisoning, environmental factors such as malnutrition environmental deprivation and child abuse/neglect” (p.13).

Acquired brain injury is a disability type that occurs as a result of neurocognitive impairment and is different from intellectual disability (Zollman, 2016). As Zollman (2016) stated, acquired brain injury emerges after birth, regardless of genetic disorders. This type of disability can occur for many different reasons, that’s why classifying acquired brain injury can vary. According to Benson and Elbaum (2007), “stroke, hypoxic injury, traumatic brain injury such as motor vehicle accidents, falls, sporting injuries, assault, degenerative disorders including alzheimer's disease, parkinson's disease, multiple sclerosis, brain tumors, infections and brain diseases such as meningitis and encephalitis” are the types of acquired brain injury (p.6). In addition to these, foetal alcohol spectrum disorder is another type of acquired brain injury that occurs during pregnancy (Zollman, 2016). As Zollman (2016) emphasized, considering all these types, the most common acquired brain injury type is stroke.

Neurological disability is the decrease and loss of mental or bodily functions due to damage to the nervous system (Alberta Human Resources and Employment, 2006).

As emphasized by WHO (2006), it usually gets worse and is very unlikely to improve. Neurological disability can be seen at the same time as other disabilities such as physical disability or acquired brain injury. As WHO (2006) stated, neurological disability can be classified as “dementia, epilepsy, headache disorders, multiple sclerosis, neuroinfections, neurological disorders associated with malnutrition, pain associated with neurological disorders, Parkinson’s disease, stroke and traumatic brain injuries” (p.iii).

Deafblind disability is the name given to the decrease or loss of hearing and vision senses of people together and accordingly, a decrease in communication skills is observed (Kennedy and Wolff Heller, 1994). This type also can be classified under physical disability, however, because of this possible decrease in communication skills, this is analyzed under a separate disability type (Miles, 2008). According to Miles (2008), deafblindness can be present from birth. However, deafblind people may be blind since birth, then become deaf or deaf since birth, and then become blind. Many reasons can cause deafblindness such as down syndrome, usher syndrome, maternal drug abuse, AIDS and stroke (Miles, 2008).

Vision disability is a condition in which the visual acuity cannot be corrected by any surgical intervention (Naipal & Rampersad, 2018). In addition, this situation causes learning problems, especially in young people (Kooijman & Ardit, 1999). There are 285 million people with vision disability in the world and the incidence among children under the age of 18 is 1 in 1000 (WHO, 2007). According to WHO (2007), vision disability can be classified under “mild vision disability, moderate vision disability, severe vision disability and blindness”. Cataracts or any other problems affecting the cornea and retina can be the causes of vision disability (WHO, 2007).

Hearing disability is a condition in which a person loses his/her hearing ability from birth or later (Stacey et al., 2006). This type, which can also be perceived as a physical disability, is classified as a separate type because it can also affect the characters of people. According to Stacey et al. (2006), hearing disability can occur in two ways: congenital hearing impairment coming from birth and hearing impairment after birth. As Okeke (2001) stated, different causes of hearing disability include infections such as German measles (rubella), smallpox, mumps, influenza, noise and blast or brain tumors.

Speech disability is the state of not being able to speak or not being able to understand what people are saying (Tahira, 2019). This may also be a precursor to some physical or mental disabilities. According to Tahira (2019), stuttering, articulation errors, tongue-tie (ankyloglossia), apraxia, dysarthria and selective mutism are some of the types of speech disability. Tahira (2019) emphasized that while some of these types are caused by physical inadequacy, some are caused by the inadequacy of control mechanisms in the brain.

Psychiatric disability is the easiest disability type to treat (Rudnick, 2013). According to Pacific Health Systems (2021), it is seen as a medical condition and the treatment of this disability depends on the person's response to treatment. Pacific Health Systems (2021) emphasized that generalized anxiety disorder, post-traumatic stress disorder, major depressive disorder, bipolar disorder, schizophrenia, schizoaffective disorder, borderline personality disorder, narcissistic personality disorder, anorexia nervosa and binge eating disorder are the types of psychiatric disabilities.

Physical disability seems the most common disability type (Zhao et al., 2019). TUIK (2011) pointed out that 8.8% of people with disabilities registered in the National Disability Database are physically disabled. As Zhao et al. (2019) emphasized,

physical disability that is the most common type of disability, affects 1 in 7 adults in US. *Paraplegia, quadriplegia, multiple sclerosis (MS), hemiplegia, cerebral palsy, absent limb/reduced limb function dystrophy* and *polio* are the types of physical disability (National Educational Association of Disabled Students, n.d.). All these physical disability types have different features and difficulties.

2.2. Cerebral Palsy as a Physical Disability

Amongst physical disability types, Cerebral Palsy (CP) is the most common physical disability that affects 2 out of every 1000 children in developed countries (Johari et al., 2016). As Gage et al. (2014) stated, musculoskeletal problems are the main problems for a person with cerebral palsy. *Spasticity, delay in developmental milestones, posture and movement problems, developing soft tissue contractures and bony deformity* are the main physical and musculoskeletal problems for a person with cerebral palsy (Johari et al., 2016, p.1281). In addition, as Rosenbaum (2006) emphasized, people with cerebral palsy may have impaired perception and behavior, or poor communication skills. There may also be other disability types that accompany cerebral palsy such as epilepsy or visual impairments (Rosenbaum, 2006). In addition, intellectual impairments are one of the problems that may be seen in people with cerebral palsy. However, it is hard to categorize the people with CP according to having intellectual impairment because this impairment can be seen in every categories of CP (Paulson & Vargus-Adams, 2017).

Cerebral palsy can influence person's posture, balance, communication, learning abilities and performing daily activities (Alliance, n.d.). Also, as Alliance (n.d.) emphasized, one in three people with cerebral palsy is unable to walk, one in four is unable to talk, one in ten has a severe vision impairment, three in four experience

pain in any part of their bodies, one in four has epilepsy and one in two has an intellectual impairment. As Tek and Ünsal (2017) pointed out, in Turkey, the incidence of cerebral palsy was determined as 4.4 per 1000 live births in the most comprehensive study. Although there are a great number of children living with cerebral palsy, fortunately, the study by Wong et al. (2004) indicated that “with improving medical care, the 20-year survival rate of children with cerebral palsy is estimated to be 85%” (p.887).

According to Johari et al. (2016), cerebral palsy can be categorized according to topography, movement disorder and function. According to the topography, cerebral palsy is classified as monoplegia, hemiplegia, diplegia, triplegia and quadriplegia while according to movement disorder, it is classified as spastic, hypotonic, hyperkinetic, ataxic and mixed. Considering functional classification, three different classifications can be made: gross motor function, upper limb function and communication. Among these category systems, the most basic and understandable classification is gross motor functions which is the one that represents the skills and limitations (Tek and Ünsal, 2017). According to Johari et al. (2016), under The Gross Motor Functional Classification System (GMFCS), there are five different levels including “GMFCS Level 1, GMFCS Level 2, GMFCS Level 3, GMFCS Level 4 and GMFCS Level 5” (p. 1282). To describe it most simply and understandably:

Level 1: In this level, people can walk without restrictions independently.

Level 2: In this level, people can walk with restrictions, but still independently (Ünsal & Tek, 2017).

Level 3: In this level, people can walk with a hand-held mobility device, but also they are able to sit and stand up without any assistance. Therefore, in this level,

people also can improve their muscles with the exercises so that they can walk, even slowly (Paulson and Vargus-Adams, 2017).

Level 4: In this level, people generally need support and use wheelchairs. However, they can walk short distances with personal assistance (Paulson and Vargus-Adams, 2017).

Level 5: In this level, people are transported in a manual wheelchair as hand and foot control is very poor (Tek and Ünsal, 2017).

2.3. Importance of Mobility

Mobility is one of the significant impacts affecting the quality of life of people (Early and Pedretti, 2001). Therefore, in order to increase the quality of life and create spaces for disabled people to live more comfortably, the factors affecting mobility should be taken into consideration and studies should be carried out to improve mobility. As Cook and Hussey (1995) emphasized, in order for people to perform their daily activities more comfortably, their mobility ought to be at good level.

While mobility is important for everyone, the considerations may vary for different people. For instance, according to different disability types, the use of crutches, manual wheelchairs or powered wheelchairs can be observed. As Routhier et al. (2003) indicated that among the disabled people, the most widely used vehicle is the wheelchair. According to the data collected by The World Health Organization (2008), the number of wheelchair users is estimated as 65 million in the world (Frank et al., 2010).

2.4. Being Young with Mobility Difficulties

United Nations defines young people as youth. According to the definition of youth that is done by United Nations (2008), it is the name given to the transition period from dependency to independence. The age range for youth is 15-24 (United Nations, 2008). Therefore, the transition of individuals from the stage they are dependent to independence can be called the youth stage, which covers the ages of 15-24.

Due to the developmental stage, young people with disabilities experience certain difficulties. They tend to be more affected by the negativities coming from the environment such as exclusion and judgment (WHO, 2011). As Thornicroft et al. (2007) emphasized, negative criticism or behavior from other people leads to reduced self-confidence and social participation of people with disabilities. Besides, the study conducted by Kabuta (2014) pointed out that the rate of going to school is lower for young people with disabilities than for non-disabled youth. According to Kelly (2016), this may be because of negative approaches such as bullying or the physical barriers that they encounter in the environment. For instance, one of the students in the interview that is conducted by WHO (2011) stated that “In my former school both pupils and teachers used to laugh at me when I failed to say something since I couldn’t pronounce words properly and they wouldn’t let me talk” (p.204). Another student noted that because of the attitude of the students in an ordinary school and the lack of special schools, they had to stay at home instead of going to the school (WHO, 2011). Therefore, in order to avoid these kinds of problems, and make the disabled young people’s lives easier or even ordinary, other people’s perspectives and attitudes towards people with disabilities should be improved. Also, to improve the young disabled people’s feelings and make them live in better

conditions, the spaces should be designed accessible so that they can live as their non-disabled peers. As Kelly et al. (2016) emphasized, people who are disabled should be given opportunities to the same extent as their non-disabled peers so the disabled young's can feel more independent as their peers.

According to Chamba (2000), 60% of families think that their home is not well-designed for children who live mobility difficulties. The study conducted by Routhier et al. (2003) pointed out that environment, user profile, and daily activities are some aspects that ought to be considered when evaluating wheelchair users' mobility. Architectural elements, as environmental factors, are among the factors that affect their mobility (Routhier et al., 2003). Besides, the architectural barriers that disabled encounter in their homes also affect their performance to do their daily activities because of the mobility restrictions (Routhier et al., 2003). When people's mobility is evaluated and improved according to their daily activities, they begin to feel more independent (Caesarendra et al., 2015). Considering all aspects, while evaluating the mobility of wheelchair users, the environmental barriers they encounter and their daily activities should be examined.

2.5. Level of Dependence and Related Emotions

Physical independence, which includes “safety, accessibility, flexible use, understandable, low effort, customizable and encouraging skill development”, is one of the key requirements for the living environments (Wilkinson, 2018, p.7). Although living independently is an important factor, it is often difficult for people with mobility difficulties to carry out daily living activities without help in their homes if their homes are not designed accessible (Hendy & Pascall, 2001). According to Northern Ireland Census data (2011), performing daily activities is a challenge for a

great number of 15-19 years olds disabled. According to Beresford and Oldman (2000), because most disabled young people's mobility are limited, they depend on others for their daily activities. This dependence is one of the factors that cause young disabled people to feel negative emotions such as worry, sadness, anger and guilt (Kelly et al., 2016). Thus, being independent is significant for young people with disabilities. In addition, since the self-confidence and sense of competence are weakened when the disabled young are dependent on someone, care should be taken to ensure that the spaces are accessible so that the disabled can be independent (Agarwal and Pandey, 2013).

Changing levels of dependency and ability to perform certain activities often lead to negative emotions (Thornicroft et al., 2007). For instance, when young disabled people are dependent on other people such as their families, they can feel guilty (Kelly et al., 2016). Besides this guilt feeling, as Kelly et al. (2016) stated, young people can also feel sad because of being dependent on others. Furthermore, most young people with disabilities believe that they need their parents because of living in inaccessible houses where they can't meet their daily needs alone so they become feel inadequate (Kabuta, 2014).

According to the questionnaire conducted by Kelly et al. (2016), although their families make the lives of disabled young people easier, they think that their families should give importance to their lives instead of taking care of themselves. To support that, the study conducted by Kabuta (2014) indicated that disabled young people feel unhappy about being dependent on their parents. However, living alone is a source of fear for the disabled (Kabuta, 2014). Therefore, the disabled young people's parents tend more to protect their children, which often leads to increased level of dependency (Hirst & Baldwin, 1994). However, it is important for young people with

disabilities to experience living alone in accessible designed homes so that their levels of independence increase (Perry, 2009). One of the main improvements that provide them to feel more independent is having an accessible home which can be achieved by housing adaptations (Pettersson et al., 2012). As Rahman et al. (2018) emphasized, many young people want their homes to be modified to live more independently. Therefore, in order to improve the level of independency and increase the accessibility in the home environments, the obstacles related to architectural elements in the homes should be analyzed.



CHAPTER III

HOME ENVIRONMENTS

The home environment is the space where people stay alone and can be defined as their private space (Mallet, 2004). The terms of home and house are two concepts that are often confused by many people. According to Bollnow (1963), a building is called a house when it is first built as a concrete, but when its functions are determined after it is bought by the owners and loaded with emotions, it starts to be called as home. Sekiguchi (2004) emphasized that “homes encompass the nature of home, its structure, and function, as well as phenomena in home life” (p. 3). Namely, when it is desired to examine people's activities and the functions of living spaces, the more appropriate term to be used is home (Mcgregor, 2016). According to Gilman (2002), for rest, peace and feeling comfortable, homes are the most suitable spaces. However, they may not be equally available to everyone living in the home. For instance, for disabled people, having an inaccessible home may not provide these positive emotions (Kelly, 2006).

3.1. Accessibility

Accessibility is the name given to people's ability to enter and leave their homes easily, to move freely in their home environments and to be easily adapted according to the needs of people (Wellecke et al., 2022). Unfortunately, many homes today are not able to meet the accessibility needs of people with disabilities (Wiesel, 2020).

Physical barriers encountered in home environments are important factors limiting accessibility. The most effective solution to increase the accessibility of homes is to make adaptations such as change the structure or layout of the homes (Bridge and Carnemolla, 2016). Thanks to the adaptations made at homes, both the level of independence of people with disabilities and their quality of life increase (Bridge and Carnemolla, 2016).

According to Kose (1998), around the 1960s, the idea of *design for the disabled* began to gain importance in the United States and Europe. In Japan, this approach that aims to eliminate the physical barriers for the disabled people emerged around 1970 and after that, a new approach emerged in Nordic countries that is called *normalization* (Kose, 1998). As Kose (1998) emphasized, the aim of this movement was not to separate disabled people, but to make a common design for everyone by addressing everyone's needs. It is obvious that to provide more livable spaces for the disabled, the idea of *design for all* should be applied in every space (Kose, 1998).

Design for all emphasizes that the demands of all users should be valued on equal terms (Bevan, 1995). This idea is mainly studied under the title of *Universal Design* which is a very notable concept (Demirkan & Olguntürk, 2013).

Universal design is a practical guide that places humans at the center and aims to meet their basic needs more easily (National Disability Authority, 2017). According to Demirkan & Olguntürk (2013), this approach, rather than segregating the needs of the disabled and creating spaces for them, produces designs that aim to meet the needs of all people. The universal design approach mainly consists of seven principles that are *equitable use*, *flexibility in use*, *simple and intuitive use*, *perceptible information*, *tolerance for error*, *low physical effort*, *size and space for approach and use* (The Center for Universal Design, 1997). As Demirkan &

Olguntürk (2013) emphasized, with the knowledge gained through these goals, more livable spaces can be created for all people. As a similar approach, *inclusive design* adopts the principle of making equal and diverse designs for everyone, taking into account people with different abilities (Altay & Demirkan, 2013). Thus, inclusive environments should allow everyone to carry out their activities comfortably and without any assistance. However, although these are very useful for designing accessible spaces for all people, there are no specific rules set to apply all these principles (Steinfeld and Maisel, 2012).

3.2. Activities of Daily Living

One of the significant factors to consider to investigate the mobility and level of dependence of young people with mobility difficulties is the daily activities they do (Carmona-Torres et al., 2019). Although people can do different activities in their daily life, some basic activities are done to advance and live our lives. These can be examined under two separate headings as *Basic Activities of Daily Living (BADL)* and *Instrumental Activities of Daily Living (IADL)* (Goverover et al., 2007). The BADL are fundamental and basic activities to live independently at home, which include *bathing, dressing, toileting, transferring, continence and feeding* (Gold, 2012, p.11). In addition, the IADL are more complex activities that require a higher level of autonomy and cognitive function and are necessary for independent life in the community (Carmona-Torres et al., 2019). The IADL includes *the ability to use telephone, shopping, food preparation, laundry, mode of transportation, responsibility for own medications, housekeeping and ability to handle finances* (Gold, 2012, p.30). When the main purpose of both BADL and IADL are examined, it can be associated with the ability of individuals to do these activities independently

(Figueiredo et al., 2013). According to the data indicated by Northern Ireland Census (2011), almost three percent of young people between the ages of 10-19 have diseases that limit their mobility while doing their daily activities (Kelly et al., 2016). The difficulty levels of the activities in BADL and IADL may differ according to the abilities of the people or the accessibility levels in the spaces people live (Seidel et al., 2011). For instance, the study conducted by Seidel et al. (2011) indicated that cooking and laundry require reaching, lifting, carrying and dexterity. Namely, if a person cannot do these actions, cooking and laundry may be difficult for her/him. However, for another person, difficulties experienced while doing activities may differ depending on the movements he/she has difficulty with. Thus, the difficulties that people may live in doing daily living activities should be examined by considering their abilities and difficulties in their bodies.

According to the study conducted by Carmona-Torres et al. (2019), the ADL of the participants who are wheelchair users were evaluated and compared. Among the BADL, bathing was the most difficult activity, while dressing was the second most difficult activity. Considering the activities under the heading of IADL, the most difficult activity to do for the participants was housework. Besides, when BADL and IADL activities were evaluated in general, it was seen that people had more difficulty in IADL activities. Also, in all activity types, women were found to have more difficulties than men (Carmona-Torres et al., 2019). On the other hand, according to the study conducted by Nieuwenhuijsen et al. (2009), preparing meals and dressing were the most common difficulties for young with cerebral palsy.

In the study conducted by Fänge & Iwarsson (2003), the participants who use wheelchairs experienced a house which had accessibility problems at 3 different times. In the first phase, they experienced the current state of the house. Afterwards,

adaptations such as enlarging the spaces or removing the steps were done. In the second phase, the house was experienced 2-3 months after the housing adaptation. In the last phase, the participants experienced the house 8-9 months after the adaptation. All the participants were selected from people with one or more mobility difficulties. According to the results of the study, 15 percent of the participants said that they were independent in all activities in the first phase. In addition, there was no significant difference found in overall ADL dependence between the 3 different phases. However, when the activities were evaluated separately, it was pointed out that the participants felt less dependent while having a bath in the 3rd phase compared to the 2nd phase and no other changes were observed between different adaptation levels in the home environment (Fänge & Iwarsson, 2003).

The study conducted by Lemmens et al. (2014) aimed to examine the most important goals for young with cerebral palsy (aged between 2.5-19 years). More than 100 questions were asked about the activities including ADL in the questionnaire.

According to the results, dressing was the most important goal for the youngest participants. Besides, preparing meals and personal hygiene were the most important activities for the oldest participants (Lemmens et al., 2014).

As Manton (1988) stated, the more disabled people are dependent on someone and have difficulty while doing these activities, the lower their quality of life is considered. Therefore, their level of ability to do these activities should be taken into account to increase their quality of life and enable them to live more comfortably.

Also, another important reason to examine these activities is to understand the challenges they face in the spaces because, as Wahl et al. (2009) emphasized that in a well-designed home that is suitable for disabled needs and more accessible, they can

do their daily activities more comfortably. In that respect homes should be considered with respect to their architectural elements.

3.3. Architectural Elements and Spaces in Homes

Architectural elements, are among the factors that affect the accessibility level of the home environments (Routhier et al., 2003). However, it is important to understand this term to evaluate the elements in the homes. According to Wahaj (2019), architectural elements can be classified as structural loading, substructure, superstructure, primary elements, secondary elements, finishing elements and services. Structural loading, substructure and superstructure are related to the foundation of the structure (Wahaj, 2019). Primary architectural elements include “external and internal walls, roofs and columns” (Chudley and Greeno, 2014, p.12). Also, as Hussein and Ismaeel (2021) emphasized, secondary architectural elements are more related to design elements that can be changed after the construction. For instance, “partition walls, doors, windows, glazing, skins, ceiling, aesthetic elements, interior elements as any decorative elements” are secondary architectural elements (Wahaj, 2019, p.2). In addition, paintings, floor coverings or plastering are some of the finishing architectural elements (Chudley and Greeno, 2014 & Wahaj, 2019). Considering all these architectural elements, primary elements, secondary elements and finishing elements are the elements that can affect accessibility of the spaces. For instance, the place of the internal walls or columns, as primary elements and place of the interior elements, as secondary elements, can be the factors that narrow the spaces. Therefore, the accessibility of the spaces are affected according to the place of these elements. Also, the finishing elements can affect the accessibility. For instance, having slippery floor coverings may be challenging some of the people.

Therefore, in order to have accessible spaces, all these architectural elements should be taken into consideration while designing the home environments.

Since daily living activities are related to spaces, modifying spaces in line with the needs of people with mobility difficulties can reduce the difficulties experienced while performing daily living activities (Fänge & Iwarsson, 2003). Therefore, evaluating the activities regardless of the difficulties living in the spaces can lead to incomplete or inaccurate results. Also, in support of this, as Seidel et al. (2011) stated, since the postures exhibited during the activities differ, these activities should be examined in detail and the products and spaces should be arranged accordingly. In this way, the independence of individuals can be enhanced. Therefore, before evaluating the daily activities, it is necessary to examine how convenient and accessible the spaces are for users. According to Imrie (2006), an accessible space should be “negotiable, visitable, livable and universal” (p.204). Therefore, it is important that the home environments where people feel most comfortable should be accessible. Also, in order to increase the level of independence of people, the difficulties they face at home should be reduced (Imrie, 2006). In addition, presenting accessible designs to the homeowners makes it easier to use the spaces in the home and increases the quality of the home as it increases the independence of the people (Imrie, 2006).

Considering the spaces in the home environments, entrances and circulation spaces, living rooms, bedrooms, kitchens and bathrooms are the main spaces. All these spaces can be analyzed whether they are accessible or not. Taking into account the spaces where environmental barriers seen, the spaces above will be discussed.

3.3.1. Entrances and Circulation Spaces

The entrance design of the homes is significant as this is the first space to step into the home. If people encounter difficulties in the first space, their feelings about the home may be negatively affected. Therefore, entrances should be designed accessible so that people with mobility difficulties can easily enter and exit the home. However, unfortunately, many disabled people complain about the entrances of their homes, and even say that they can't get in and out of their homes without help (WHO, 2011). According to the research that Norin et al. (2020) conducted, entrances are the first spaces where accessibility problems are the most common. On the other hand, according to Stephens et al.'s (2017) study, compared to other spaces, entrances are seen as the most accessible spaces for wheelchair users in the homes.

Encountering the stairs at the entrance, having the entrance doors too narrow or even having the slightest ledge at the entrance can create problems for people with mobility difficulties (Council of Europe Press., 1993). Other barriers seen in entrances can be “high thresholds and/or steps, doors cannot be fastened in an open position, doors do not stay in open position/close quickly or no ramp” (Norin et al., 2020, p.6). According to the study conducted by Stephens et al. (2017), the mobility of wheelchair users who do not have an elevator in their home is restricted, which reduces their level of independence.

In addition to the entrances, the circulation areas should also be accessible for the people who have mobility difficulties. Firstly, the width of the circulation areas should be arranged by considering the minimum clear width for the wheelchair users which is 915 mm continuously and the required space for turning which is 1525 mm (ADA Standards, 2010). In this way, wheelchair users can easily circulate (Perry, 1994). Also, the walls of the circulation spaces which can include corridors of the

homes, should be strengthened so that any installations can be made such as grab bars or lifts (Thomas, 2004).

There is no doubt that if there is no chance to design a fully accessible home, the existing home should be modified to live in a more accessible home (Wilkinson, 2018). As Norin et al. (2020) stated, according to the research conducted among the modified homes, entrances are the most adapted spaces with a rate of 42 percent. Ramps to entrances are by far the most preferred arrangements (Norin et al., 2020). In addition to the ramp adaptation, Imrie (2006) claimed that the most effective adaptation to make entrances accessible would be to level the courtyard area with the entrance. Also, considering that at least one entrance should be designed without a step to have a flat entrance may also be an effective solution (Imrie, 2006).

3.3.2. Living rooms

Obstacles related to architectural elements are not often encountered in livingrooms and these issues are not usually covered in articles since they are generally larger than other spaces (Norin et al., 2020). However, there are still some basic obstacles and fundamental principles that should be considered while designing accessible living rooms.

Living rooms should not contain any steps so that people with mobility difficulties can move easily. For instance, according to the participant attended to the study of Perry (1994), she couldn't access the living room of her home because the living room was sunken. As it is emphasized by ADA Standards (2010), for a wheelchair user, the minimum clear width should be 815 mm at a point and 915 mm continuously. Also, to make a 360-degree turn, the space required for a wheelchair is 1525 mm (ADA Standards, 2010). Therefore, the places of the furniture and the

width of the spaces ought to be designed according to these dimensions. In addition, as should be in other spaces, as Imrie (2006) emphasized, to provide easy access the windows, windows must be 800 mm or lower. Also, all the controls such as sockets or switches must be no more than 1200 mm above the ground (Imrie, 2006). Besides, in order not to hinder the maneuvering abilities of people and to enable them to turn and pass more easily, the edges should not be sharp, there should be soft edges. Also, considering the materials, to prevent slipping, floor materials should be selected from non-slippery materials.

3.3.3. Bedrooms

Considering the time we spend in our homes, bedrooms can be considered as one of the spaces where people spend the most time alone (Çınar et al., 2015). As Imrie (2006) stated, bedrooms are spaces of regeneration and purification, both physically and mentally. Any activity that a person wants to do alone in the room, such as dressing, which is one of the Basic Activities of Daily Living (BADL), studying, reading a book or watching outside, can increase the time spent in the bedroom.

Since people spend most of their time in bedrooms alone, great importance should be given to accessibility in this space so that people with mobility difficulties can do activities by themselves without the need for help.

In bedrooms, there are many factors that make people who use crutches or wheelchairs dependent on others and affect their mobility. For instance, in a survey study conducted by Stephens et al. (2017) involving disabled participants, one of the participants stated that because her wheelchair couldn't fit between the beds, her mother had to carry her when she went to bed and got out of the bed. That's why she said that the first adaptation her mother wanted to apply in their home was the ceiling

lift so that her daughter could get up and go to bed independently. Besides, her mother mentioned that some of the later adaptations, such as expanding the lounge area or moving sockets and light switches within reach of a wheelchair user, made her daughter's life easier and increase her mobility (Stephens et al., 2017).

According to the interview with wheelchair users conducted by Imrie (2004), some participants stated that they could not pass between beds with their wheelchairs because they did not have large spaces in their bedrooms, and this mobility difficulty angered them. One of the participants stated that he could not reach the other side of the bed in the bedroom, nor could he reach the window in the bedroom, which angered him and made him feel neglected (Imrie, 2004).

Çınar et al. (2015) conducted a study to understand the problems experienced by wheelchair users in their bedrooms. A questionnaire was applied to 50 wheelchair users. According to the results of the research, the maneuver ability, the use of upper parts of the wardrobes, access to the bedroom window handles and transfer to bed were the difficulties that the participants stated. Among these difficulties, the most difficult activities were the use of wardrobes and transfer to bed.

In the research conducted by Stineman et al. (2007), an apartment was arranged in two different accessibility levels and experienced by the wheelchair user participants at different time intervals. In the accessible version of the apartment, considering the bedroom, a wider bedroom doorway and a lower coat rack were preferred instead of narrow doorways and standard coat racks. As a result of these improvements, it was observed that the participants needed others' help less, felt more independent and were able to perform daily activities more effectively.

Many studies' findings indicate that accessibility problems in bedrooms make it difficult for people to do their daily activities, as in other spaces. For this reason, it

can be said that among those who have mobility difficulties, people who have the opportunity, want to make changes/adaptations, even small ones, in their homes (Stineman et al., 2007). According to Norin et al. (2020), although bedrooms are not one of the first three areas where environmental barriers are the most common, they are the third of the first three spaces where the adaptations are seen the most by adding ceiling lifts in existing homes. Also, widening the doorway of the bedrooms or enlarging the bedrooms can be recommended as it will provide wheelchair users more space to move around (Stineman et al., 2007).

3.3.4. Kitchens

Considering that meal preparation is one of the instrumental activities of daily living (Graf, 2008), it is important to design kitchens in an accessible way so that wheelchair users can be self-sufficient. However, many studies reviewed indicated that wheelchair users are dissatisfied with the accessibility of their kitchens. For instance, according to the results of the survey conducted by Stephens et al. (2017), with the participants aged 8-14, using at least one mobility device, 90% of the participants had issues accessing the kitchen counter or the kitchen cabinets to take plates in their kitchens. In addition, one of the participants, using a wheelchair, stated in the interview with Imrie (2004) that because the kitchen cabinets, countertops and the cooker were high for a wheelchair user, it was very difficult to prepare the meals and this is making her upset. Another participant had difficulty in turning with a wheelchair because of her small kitchen, and this situation made it difficult for her to maintain her own life without the help of others (Imrie, 2004).

In the study conducted by Imrie (2006), one of the participants who use a wheelchair stated that while she was using a standard kitchen before, and then she modified her

kitchen. After this adaptation, she realized that this contributed greatly to her level of independence (Imrie, 2006). She stated that in her modified kitchen, her mobility became increased due to knee space under kitchen counters, lower counters, and all fixtures in the kitchen being moved to spaces suitable for wheelchair use (Imrie, 2006).

The above studies reveal the problems experienced by wheelchair users due to the inaccessibility of the kitchens. As Norin et al. (2020) highlighted, kitchens are the second space, after entrances, where environmental barriers are seen the most. Also, the fact that “wall-mounted cupboards and shelves placed high in the kitchen” are the most common obstacles for the participants (Norin et al., 2020, p.768). To support that, the inaccessibility of high kitchen cabinets is also mentioned in the study conducted by Allen et al. (2006). In addition, as Stineman et al. (2007) stated, it was determined that the lower positioning of the kitchen cabinets facilitated the mobility of the participants who are wheelchair users. Supporting that, adjustable-height counters and rollout shelving can also be some examples that will be beneficial to use the kitchen more flexibly (Imrie, 2006).

Considering the facilitations in the kitchens increase the mobility of wheelchair users, it is advisable to make some adaptations as mentioned above. On the other hand, as a divergent opinion expressed in the study conducted by Hertig-Godeschalk et al. (2017), more than seven percent stated that the kitchen doesn't need to be accessible if another person in the home is helping with their chores in the kitchen. Although such an opinion is not very common, it can be deduced that the arrangements related to accessibility in homes may vary depending on the daily activities and preferences of wheelchair users as well as the household composition.

3.3.5. Bathrooms

Bathrooms are one of the most private spaces where people should be alone.

However, when people with mobility difficulties face obstacles that they cannot overcome, it can become difficult to meet their needs in the bathroom without help.

According to the research conducted by Norin et al. (2020), bathrooms are the third spaces, after entrances and kitchens, where environmental barriers are seen the most in the homes. To support that, nearly 90% of the participants who attended the study conducted by Stephens et al. (2017) stated that they encountered at least one obstacle in their bathrooms and this affects their mobility.

Examples can be given that restrict the mobility of wheelchair users and cause the bathroom to become inaccessible for them. For instance, “no grab-bar at shower and toilet, controls in inaccessible position” are the most frequently reported obstacles in the bathrooms (Norin et al., 2020, p.6). In addition to that, according to the participants who attended the study by Stephens et al. (2017), “inaccessible taps or mirrors and absence of roll-in showers or tub seats” are also some of the obstacles that restrict their mobility in the bathroom (p.590). Small bathrooms and the height of the sink are the factors that hinder having an accessible bathroom (Allen et al., 2006). Besides, sometimes people may experience different emotions when faced with such difficulties, such as one of the participants who attended the research of Imrie (2004) said that she had difficulty in using the bathroom because there was not enough space in the bathroom and that's why she felt unhappy.

In the research conducted by Çınar et al. (2015), 50 participants participated in a survey in which they evaluated the bathrooms in their homes. According to the results, the ability of maneuvering, slippery floors, accessing the shower head, use of

shower cabins and use of Turkish style toilets (type of toilets that users need to squat to use them) are the most difficult features in the bathrooms.

Considering that bathrooms are private spaces and people want to move freely in bathrooms on their own, it would be useful to make various arrangements to provide more accessible bathrooms. According to Stephens et al. (2017), bathrooms are the first spaces many people want to change in their homes. To support that, as Norin et al. (2020) emphasized, after entrances and kitchens, the most modified spaces are bathrooms by wheelchair users. “Angle-adjustable washbasin, washbasin extended from wall and wall-mounted toilet armrests” are the most common adaptations that are applied in the bathrooms (Norin et al., 2020, p.769). Since the mobility of wheelchair users is important to carry out their daily activities, Norin et al. (2020) highlighted that these arrangements should be considered as important adaptations because they increase the mobility of wheelchair users.

Literature review revealed that there are various studies about the independence of the people who live mobility difficulties according to the total success in the activities. There are not many instances of the comparison of the activities separately. Especially considering the cerebral palsy, it was seen that the comparisons were very few for activities of daily living separately and the current total independency comparisons were generally made according to the GMFCS levels of the cerebral palsy. Also, there was no survey study found in the literature aimed at understanding the feelings of young people with cerebral palsy while doing daily activities and very few articles were found to examine the importance they attach to activities (Lemmens et al., 2014). Therefore, different questions from the literature were added to this study to compare the activities among themselves

including difficulty levels, level of dependence and related emotions and importance levels. In this way, it is aimed to obtain a significant study.



CHAPTER IV

METHODOLOGY

In this study, the main aim is to understand what young people with cerebral palsy experience while doing daily activities. By exploring the experiences while doing daily activities, it is aimed to understand the difficulty levels in doing daily activities, participants' level of dependence and related emotions, and the importance levels that they give to the activities. In the methodology part, after the daily activities of the participants are examined separately and in detail, the activities are compared among themselves. In this way, the activities that people find the most difficult and most important are determined. In this context, the activities in which people feel most dependent and how they feel when they are dependent on others also emerge. In addition, the relationships between these factors are discussed.

4.1. Research Questions and Hypotheses

After evaluating the information obtained from the literature and the emerging gaps, the research questions and hypotheses are formed. Along with the determination of the gaps, the examination of some relationships that are not discussed in the literature is also added to the questions. The research questions can be grouped under three main headings including difficulty levels, level of dependence and the related emotions, and importance levels. The first three research questions are specified to explore these three main headings. The rest of the research questions (RQ4-7) are aiming to examine the relationships between these main headings. Also, four

hypotheses are determined considering the correlations of these main headings (Figure 1). In the light of the information obtained from the literature and the determined gaps, in this study, answers to the following questions and hypotheses are established:

RQ1. What level of difficulty do young people with CP have while performing daily activities in their homes?

RQ2. What level of dependence do young people with CP have while performing daily activities in their homes?

RQ2a. What are the emotions that emerged according to the dependency?

RQ2b. What are the adaptations in the homes to increase independency?

RQ3. What level of importance do young people with CP have while performing daily activities in their homes?

RQ4. Is there a relationship between the difficulties young people with cerebral palsy experience in their bodies and the difficulties they experience in the activities?

RQ5. Is there a relationship between the difficulties young people with cerebral palsy experience while doing daily activities and their level of dependence?

RQ6. Is there a relationship between the difficulties young people with cerebral palsy experience while doing daily activities and the importance level they give to the activities?

RQ7. Is there a relationship between the level of dependence of young people with cerebral palsy and the importance level they give to the activities?

H1: There is a positive correlation between the difficulties young people with CP experience in their bodies and the difficulties they experience while doing daily the activities.

H2: There is a positive correlation between the difficulties young people with CP experience while doing daily activities and their level of dependence.

H3: There is a positive correlation between the difficulties young people with CP experience while doing daily activities and the importance level they give to the activities

H4: There is a positive correlation between the level of dependence of young people with CP and the importance level they give to the activities.

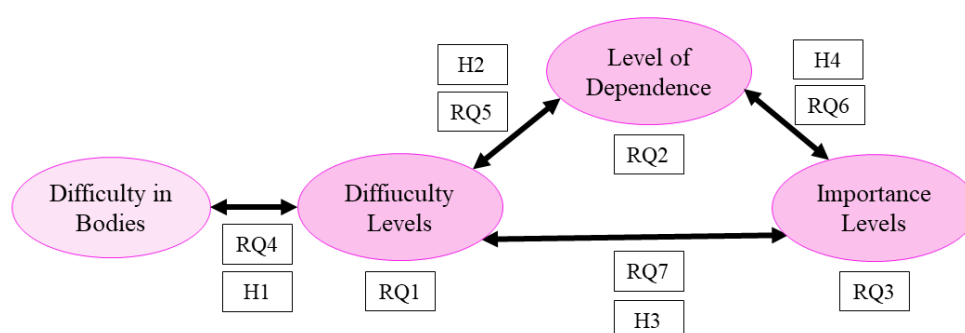


Figure 1. The research questions and hypotheses according to related headings (Drawn by author, 2022).

4.2. Study Procedure

This study consists of eight main stages. The first five stages represent the preparation phase for the study. Stages 6 and 7 represent the data collection phase and the final stage creates the analyses phase (Figure 2). In alignment with the literature review, the first step was to determine the GMFCS levels of people with cerebral palsy to be selected as participants. In addition, in this stage, among the activities gathered under the titles of ADL and IADL, activities that specifically required furnishing in the home environments, including preparing meals, getting dressed, doing laundry, using the toilet and taking a bath, were selected to ask the participants in the survey. In order to understand interior architectural problems and suggest additional solutions, the activities that require design elements were selected. In the second stage, survey questions were prepared by taking into account the selected activities and the inferences made after reviewing the literature. In the third stage, a pilot study was applied to the acquaintances in the environment by using the convenience sampling method. After the data was collected in the pilot study, the survey questions were revised. In the stage four of the study, Serçe v officials were contacted to request a petition of cooperation and a document was obtained (see Appendix A). Serçe v (Association of Children with Cerebral Palsy) was established in 2002 in Ankara. It is an association with the status of association for the public benefit. It continues its activities with 1700 members and a network of nearly 500 volunteers. It carries out studies to ensure that children with Cerebral Palsy benefit from their rights in education and health at the maximum level (Serçe v, n.d.). In the fifth stage, approval was obtained by İhsan Doğramacı Bilkent University's Ethics Committee. (see Appendix B). Thus, the preparation phase was completed and the data collection phase was started.

After receiving the approval, in the sixth stage of the study, the Serçeşme officials were contacted again and the quota sampling method was applied to select the participants of the survey. Then, the survey questions were sent online to the participants who were eligible to participate in the study. Along with the survey questions, consent forms were also sent to the individuals online. In addition, the survey included a final question of a voluntary invitation to a further interview. The participants who responded positively to the invitation participated in the interview in the stage seven. Thus, the necessary data for the study were collected and the analysis phase was started.

In the last stage, various analyzes were carried out to examine all the collected data from the survey and interviews. At first, the frequency tests for the descriptive statistics were used. After that, Spearman's Correlation Coefficient tests were carried out to examine the relationships between the various situations. Finally, in order to analyze the qualitative data collecting from open-ended survey questions and interviews, content analysis was used.

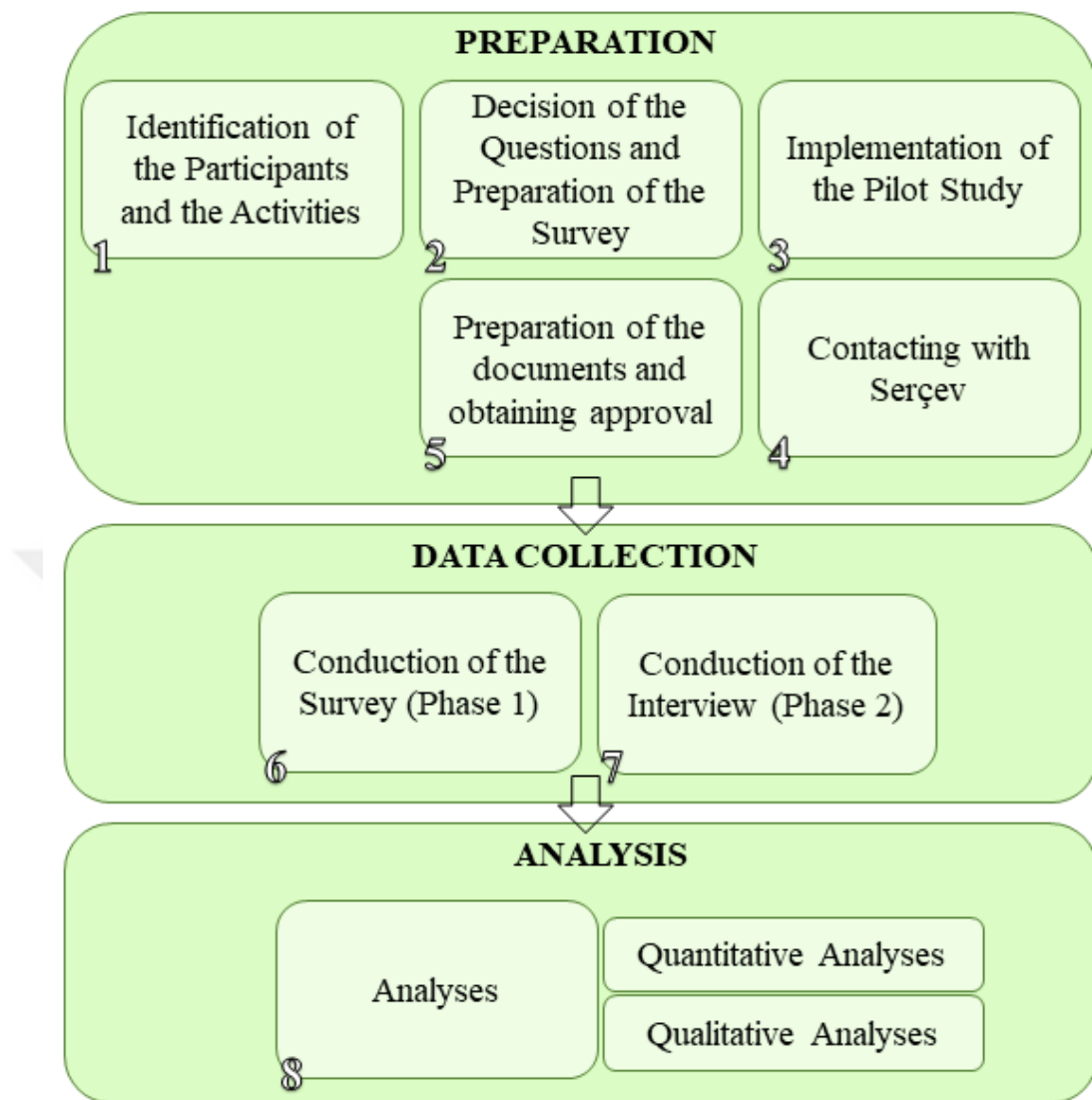


Figure 2. The stages of the study (Drawn by author, 2022).

4.3. Sampling Procedure

4.3.1. Phase 1: Survey

In order to select the participants and to send the prepared survey to the participants, the Serçev management was contacted. It was taken into account that individuals with cerebral palsy have different levels of mobility. Considering that the questions of the survey will measure how much difficulty people with cerebral palsy have in

performing daily activities, it was determined that the approaches of people with cognitive difficulties will be different from those with only physical impairments. Therefore, it was decided to select only the young people with cerebral palsy who are only physically impaired. In management resources, no records of people with cerebral palsy were found to have disability levels and whether they have intellectual impairments. However, there was a Whatsapp group with the parents of people with cerebral palsy who were members of the Serçev. This separation was made by asking the parents of the participants. Since people with certain characteristics and belonging to a certain group are expected to participate in the study, the quota sampling method was used in the selection of participants (Taherdoost, 2016). It was considered that cerebral palsy includes five different levels, and those at the first and second levels could move without assistance, but those with the third and fourth levels mostly use crutches or wheelchairs if they were not improved their muscles. Those who are at level five seem to need much greater help and less able to control hands and feet (Johari et al., 2016). Therefore, people with cerebral palsy at level three and level four were selected to participate in the study. Also, as United Nations (2008) emphasized, the age range of youth which is 15-24 is the transition period from dependency to independence so the participants were selected from the age range of 15-24. Apart from these, no other restrictions were used in the selection of participants.

Through Serçev officials, online survey questions were shared in the Whatsapp group, and the characteristics of people with cerebral palsy who are eligible to participate were explained in terms of age or cerebral palsy level. There were 100 parents of young people with cerebral palsy in this group. After the survey was shared in this group, 31 young people with cerebral palsy participated the survey.

In this study, the average age of the participants is 21. 51.6% of the participants are female, 48.4% are male, 29% are students, 48.4% are working and 22.6% are not working. While 96.8% of the participants live in an apartment, 3.2% in a detached house and 9.7% live alone. While 16.1% of the participants do not use any mobility device, 19.42% use crutches, 19.42% manual wheelchairs and 45.2% use powered wheelchairs (see Table 1).

Table 1. Distribution of the participants' demographic characteristics (n=31)

Characteristics	Category	f	%
Age	15-18	5	16,1
	19-24	26	83,9
Gender	Female	16	51,6
	Male	15	48,4
Working Status	Student	9	29,0
	I am working	15	48,4
	I am not working	7	22,6
Type of House	Apartment Flat	30	96,8
	Detached House	1	3,2
Living alone	Yes	3	9,7
	No	28	90,3
Using mobility device	I don't use	5	16,1
	Crutches	6	19,4
	Manual wheelchair	6	19,4
	Powered wheelchair	14	45,2

4.3.2. Phase 2: Interview

Six people who found it appropriate to participate in the interview were interviewed as a focus group in the study. Since the ideal number to be considered as a focus group in non-commercial matters is between 5-8 people (Krueger, Casey, 2000), having six participants to be a focus group was deemed suitable for this study. Online interview dates were determined with the participants. While four of the six people

who participated in the interview were young people with cerebral palsy, the remaining two were the parents of young people with cerebral palsy. Since the people participating in the interview were selected from among the people who participated in the survey, the age range and cerebral palsy levels of the participants were the same as the participants in the survey. In addition, the diversity of the mobility devices used by the participants in the interview added diversity to the study. While one male participant does not use any mobility device, two (one male and one female) participants use crutches, and one female uses a wheelchair. The children of both parents participating in the interview are wheelchair users with cerebral palsy.

4.4. Setting

The setting of the study was online because finding the participants for an online survey and interview was easier than carrying out the survey and interview face to face. The survey was sent to the participants by sharing a link with participants. Then, they answered the questions online. Also, interviews were carried out by making phone calls with the participants at the designated times. As stated earlier, Serçe v was the supporting association whose database and support provided communication.

4.5. Instruments

4.5.1. Phase 1: Survey

A consent form was prepared in Turkish for the people who agreed to participate in the survey, together with the survey questions to obtain participants' approval to attend the study. Considering that the age range of the participants is 15-24, two

separate consent forms were created for the participants who are aged between 15-17 to obtain the consent of their fathers and mothers separately. In these consent forms, in addition to the consent of the parents, there was also a part for the consent of the participant (see Appendix C and D). In addition, considering that the participants aged 18 and over are adults, a separate consent form was prepared for them (see Appendix E). These consent forms were shared with the participants during the survey process.

While preparing the survey questions, the questions that emerged in the literature review and were found suitable for this study were revised. After the *demographic questions (section 1)*, for the daily activities that are included in the content of the questions, KATZ ADL and Lawton index were analyzed. As mentioned in 4.2. *Study Procedure*, activities that specifically required furnishing in the home environments, including preparing meals, getting dressed, doing laundry, using the toilet and bathing, were selected to ask the participants in the survey. In order to understand interior architectural problems and suggest additional solutions, the activities that require design elements were selected. The content and definitions of the chosen activities were prepared in the survey by considering KATZ ADL and the Lawton index (Shelkey & Wallace, 1999 & Graf, 2008). *The Physical Awareness Questions (section 2)* were prepared by referencing “Fundamental Principles of Official Statistics” (Economic and Social Council, 1994). This part was created to understand the disability levels of the participants and accordingly, which part of their body they have difficulty in using. *The Difficulty Questions (section 3)* were prepared by revising the reference questions from WHODAS 2.0 questions (WHO, 2010) that are created by considering The International Classification of Functioning, Disability and Health (ICF) index. This part aims to examine which

daily activities the participants have more difficulty in doing. To prepare *The Dependency Questions (section 4)*, KATZ ADL and Lawton index were taken as references (Shelkey & Wallace, 1999 & Graf, 2008). In this survey part, participants evaluate their level of independence in their homes and these questions help to understand whether participants feel dependent on someone. The questions of the last part of the survey which is *Importance Questions (section 5)* were created by referencing the questions from the survey that Demirkan & Olguntürk (2013) prepared. The questions that they used were generalized and revised to understand which activities participants give more importance to. In the survey, the questions other than demographic factors questions and some questions in the difficulty questions part were asked in five Likert scales. Besides, there are also open-ended questions in the survey to analyze the participants' opinions and feelings in detail. In the light of the information from the literature and the questions received for revision, the survey was first prepared in English, then translated into Turkish for the participants (see Appendix F and G). The survey consisted of five sections including *Demographic Questions (section 1)*, *Physical Awareness Questions (section 2)*, *Difficulty Questions (section 3)*, *Dependency Questions (section 4)* and *Importance Questions (section 5)*. The questions were created with great care and sensitivity in order not to affect the participants negatively.

4.5.2. Phase 2: Interview

Making an interview in addition to the open-ended survey questions added a different and deeper dimension to the research. In the interview, which proceeded with the guidance of the participants without being limited to the survey questions, points that were not considered before were mentioned. In addition, making long and

detailed explanations in the interview provided more information than the open-ended questions given in the survey questions.

According to the plans made before the participants were contacted, the interview was scheduled as an online video interview. Accordingly, a consent form was created in order to obtain confirmation whether the participants agreed to the video interview. However, after communicating with the participants who agreed to participate in the interview, it was decided to conduct the interviews by phone calls, since they did not use any online video applications. Therefore, the consent forms of the interviews were modified as a phone call interview instead of a video call interview. Similar to the consent forms created for the survey, the consent forms for interviews were prepared (see Appendix H, I and J). These consent forms were shared with the participants before the phone call to obtain their consents. This consent forms also include the approval part for the record of the phone call. Although main interview questions were based on the overall open-ended survey questions, the questions and conversations were mainly shaped according to the differences in the issues emphasized by the participants. In this way, different interview contents were provided to each participant. Because the contents of the interviews change according to the responses of the participants, the times allocated for the interviews also varied. Considering the interviews, the average time was calculated as 12 minutes.

4.6. Pilot Study

Before the survey and interviews were conducted with the participants, a pilot study was carried out to test the suitability of the questions and to increase the efficiency of the study. First of all, wheelchair and crutch users were reached by using the

convenience sampling method from the environment and acquaintances in order to determine the participants to whom the survey questions would be sent. After 5 participants aged between 20-30, using crutches and wheelchairs were determined, the online survey questions were sent to the participants. They were asked to answer and evaluate the questions whether the questions are efficient or not. Also, they were asked to assess whether the questions will have a sensitive impact on people. After the participants of the pilot study completed the survey, they were contacted and their feedback was received, so some revisions were made in the survey according to their feedback.

First of all, before the pilot study, among the survey questions, the questions in *Section 3: The Difficulty Questions* included questions asking whether people could do the activities. However, there was no part that asked why they could not do the activities. In the pilot study, most of the participants replied to the questions as "We don't prepare meals" or "We don't do the laundry". However, it was not clear if it was because of their inability or because they don't prefer to do. Some of the respondents stated that "I do not prepare meals because I do not like cooking" or "I do not do laundry because my mom does". After considering these answers as these are not related to the people's abilities, some open-ended questions asking why they don't do were added after asking whether they can do the activities. Also, the number of open-ended questions was increased asking why they don't do it and how they feel.

Secondly, before the pilot study, the contents of the activities in the questions included in *Section 3: The Difficulty Questions* were not explained to the participants. The questions only were asked "Can you prepare the meals without help" or "Can you get dressed without help". After the feedback from the participants of the pilot study, it was realized that the terms of meal preparation and doing

laundry were not clearly understood by the participants. Therefore, while the survey was being revised, the activities were explained with details in parentheses.

Finally, in the survey created before the pilot study, the last section consisted of accessibility questions. During the pilot study, participants stated that they could not fully understand the questions asked because of the ambiguity of the meaning of the term accessibility. Therefore, as a revision, it was thought to write the definition of accessibility at the beginning of the section. However, then, it was decided to remove the questions about accessibility because of other feedback from the participants about the length of the questions. It was concluded that in many questions in the survey, similar questions related to accessibility were already mentioned, so there was no need for a separate section. Thus, a shorter, more compact and understandable survey was obtained after the feedback of the pilot study's participants.

After Ethics approval that was obtained at the end of March 2022, the survey phase was started and sustained four weeks. Afterwards, interview sessions were conducted in a total of four weeks within April and May 2022.

CHAPTER V

RESULTS

5.1. Results of the Survey

SPSS 22.0 Program was used for the analysis of the data collected within the scope of the research. Frequency analysis was used to determine the percentage distribution of the answers given by the participants to the research questions. Spearman's Correlation Coefficient Test was used to examine the relationships between participants' difficulties in daily living activities, their dependence on others and emerged emotions because of this dependence and the importance of being able to do the activities themselves. In this study, the variables are in an ordinal scale.

Therefore, carrying out the Spearman's Correlation Coefficient Test was the most suitable test for the correlations (Hauke & Kossowski, 2011). In Spearman's Correlation Coefficient Test, the r value is checked to measure the strength of the relationship between the variables. According to Hinkle et al. (2003), the r value between 0,0-0,3 refers to negligible correlation, 0,3-0,5 refers to low correlation, 0,5-0,7 refers to moderate correlation, 0,7-0,9 refers to high correlation and 0,9-1 refers to very high correlation.

In order to test the reliability of the questions about these correlations, Cronbach's alpha reliability test was used. According to Shamsuddin et al. (2015), when the Cronbach alpha value is between 0,6-0,7, it is considered moderate reliability. It is also called good reliability when it is between 0,7-0,8. The reliability tests was done for each group of the questions. The result of the Cronbach's alpha value for the

questions about physical difficulties in bodies (6 items; Q8) is 0,765 so it is a good level to have a reliable results. The result of the Cronbach's alpha value for the questions about level of the difficulties in doing activities (5 items; Q14) is 0,744 so it is a good level to have a reliable results. The result of the Cronbach's alpha value for the questions about level of dependency and related emotions (8 items; Q24) is 0,721 so it is a good level to have a reliable results. The result of the Cronbach's alpha value for the questions about importance levels of daily activities (5 items; Q28) is 0,667 so it is a moderate level to have a reliable results.

5.1.1. Quantitative Analysis

As quantitative analysis, descriptive statistics were carried out to examine RQ1-RQ3. In these analyses, "Strongly Disagree, Disagree, Neutral, Agree and Strongly Disagree" which are placed in 5 Likert scales are seen in the tables. However, in the explanations, disagree and strongly disagree, and agree and strongly agree are combined to have more compact and clear explanations.

All analyses and the tables were done by considering the total number of participants, 31 people. In addition to these analyses, since 5 of the participants stated that they do not use any mobility devices, the answers of these 5 participants were discussed separately in addition to the total analysis. This analyses were carried out separately to examine whether there is a difference between the results for all participants and those who do not use mobility devices.

5.1.1.1. Physical Difficulties with the Bodies of the Participants

The first set of results are related to the physical difficulties that participants experience in their bodies and were formed from the answers of questions 1-7 belonging to the physical awareness questions in the survey (see Table 2).

Table 2. Percentage distribution of the responses to the physical awareness questions (n=31)

Physical Difficulties with the Bodies	1	2	3	4	5	Mean ($\bar{x}$)	SD (σ)
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
I have difficulty in using my arms.	12,9	41,9	9,7	25,8	9,7	2,77	1,26
I have difficulty in using my hands.	25,8	35,5	9,7	19,4	9,7	2,52	1,34
I have difficulty in using my legs.	9,7	0,0	6,5	58,1	25,8	3,9	1,11
I have difficulty in holding/using objects.	29,0	38,7	12,9	12,9	6,5	2,29	1,22
I have difficulty in using my wheelchair/crutches.	38,5	42,3	11,5	7,7	0,0	1,88	0,91
I have difficulty in moving around without any assistance.	38,7	29,0	16,1	12,9	3,2	2,13	1,18

The difficulty with the highest mean value is highlighted.

To the statement “I have difficulty in using my arms”, while 54,8% disagree, 9,7% are neutral, 35,5% agree. To the statement “I have difficulty in using my hands”, 61,3% disagree, 9,7% are neutral, 29,1% agree. To the statement “I have difficulty in using my legs”, 9,7% of the respondents disagree, 6,5% are neutral, 83,9% agree. To the statement “I have difficulty in holding/using objects”, 67,7 of the respondents disagree, 12,9% are neutral, 19,4% agree. To the statement “I have difficulty in using my wheelchair/crutches”, 80,8% of those who participated in the research and used

wheelchairs/ crutches gave the answer of disagree, 11,5% neutral, 7,7% agree. To the statement “I have difficulty in moving around without any assistance”, 67,7% of the respondents gave the answer of disagree, 16,1% neutral, 16,1% agree (see Table 2).

Considering the means of the difficulties experienced by the participants in their bodies, it is found that the part of the body that the participants had the most difficulty with is the legs with the mean value of 3,9.

To analyze whether the results of people who did not use mobility devices change, their results were also analyzed separately (see Table 3).

Table 3. Percentage distribution of the responses to the physical awareness questions (n=5)

Physical Difficulties with the Bodies	1	2	3	4	5	Mean ($\bar{x}$)	SD (σ)
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
I have difficulty in using my arms.	40	20	0,0	20	20	2,60	1,81
I have difficulty in using my hands.	60	0,0	0,0	20	20	2,40	1,94
I have difficulty in using my legs.	40	0,0	0,0	20	40	3,20	2,04
I have difficulty in holding/using objects.	60	0,0	0,0	0,0	40	2,60	2,19
I have difficulty in moving around without any assistance.	60	0,0	20	20	0,0	2,00	1,41

It is seen that to the statement “I have difficulty in using my arms”, 60% of the respondents disagree and 40% of the respondents agree. To the statement “I have difficulty in using my hands”, while 60% of the respondents disagree, 40% of the respondents agree. To the statement “I have difficulty in using my legs”, 40% of the

respondents disagree and 60% of the respondents agree. To the statement “I have difficulty in holding/using objects”, 60% of the respondents disagree and 40% of the respondents agree. To the statement “I have difficulty in moving around without any assistance”, 60% of the respondents disagree, 20% of the respondents neutral and 20% of the respondents agree (see Table 3).

Considering the mean values of the difficulties in the bodies, it can be stated that “difficulty in using legs” has the highest mean value for the participants who don’t use mobility devices.

5.1.1.2. Ability to do Daily Activities without Assistance

The results of *ability to do daily activities without assistance* were formed from answers of questions 9-13 belonging to the *difficulty questions* in the survey (see Table 4).

Table 4. Percentage distribution of daily activities that participants could or couldn't do without assistance (n=31)

Ability to do the Daily Activities	Can do	Can't do
Preparing meals	45,2	54,8
Dressing	90,3	9,7
Doing Laundry	32,3	67,7
Using the Toilet	87,1	12,9
Taking bath	67,7	32,3

Examining which activities the participants can and which they cannot do without assistance, 54.8% of the participants stated that they can’t prepare meals without assistance, 9.7% of the participants stated they can’t get dressed without assistance,

67.7% of them stated they can't do laundry without assistance, 12.9% of them are not being able to use the toilet and 32.3% of them can't take a bath without assistance (see Table 4).

To analyze whether the results of people who did not use mobility devices change, their results were also analyzed separately (see Table 5).

Table 5. Percentage distribution of daily activities that participants could or couldn't do without assistance (n=5)

Ability to do the Daily Activities	Can do	Can't do
Preparing meals	40	60
Dressing	60	40
Doing Laundry	40	60
Using the Toilet	100	0,0
Taking bath	60	40

It is seen that 60% of the participants can't prepare meals without assistance, 40% of the respondents can't get dressed, 60% of the respondents can't do laundry and 40% of the respondents can't take a bath without assistance. All the respondents stated that they are able to use the toilet without any assistance (see Table 5).

5.1.1.3. Difficulty Levels For Each Activity

The results of *difficulty levels for each activity* were formed from answers of question 14 belonging to the *difficulty questions* in the survey (see Table 6). The aim of these results was to examine RQ1.

Table 6. Percentage distribution of the responses to the questions about difficulty levels of daily activities (n=31)

Daily Activities	1	2	3	4	5	Mean ($\bar{x}$)	SD (σ)
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
I have difficulty preparing meals.	12,9	22,6	16,1	29,0	19,4	3,19	1,35
I have difficulty getting dressed.	45,2	35,5	12,9	6,5	0,0	1,81	0,91
I have difficulty doing laundry.	0,0	12,9	19,4	35,5	32,3	3,87	1,02
I have difficulty using the toilet.	41,9	29,0	12,9	3,2	12,9	2,16	1,37
I have difficulty having a bath.	35,5	22,6	9,7	12,9	19,4	2,58	1,57

The difficulty with the highest mean value is highlighted.

To the statement “I have difficulty while preparing meals”, 35,5% of the respondents answered disagree, 16,1% neutral, 48,4% agree. To the statement “I have difficulty getting dressed”, 80,7% of the respondents gave the answer of disagree, 12,9% neutral and 6,5% agree. To the statement “I have difficulty doing laundry”, 12,9% of the respondents gave the answer of disagree, 19,4% neutral, 67,8% agree. To the statement “I have difficulty using the toilet”, 70,9% of the respondents gave the answer of disagree, 12,9% neutral, 16,1%. To the statement “I have difficulty having a bath”, 58,1% of the respondents gave the answer of disagree, 9,7% neutral, 32,3% agree (see Table 6).

Considering the means of the difficulties experienced by the participants while doing daily activities, it is found that doing laundry is the most difficult activity with the mean value of 3,87. Besides, getting dressed is the least difficult activity with the mean value of 1,81.

The results obtained from the question (Q15) in which participants were asked to indicate the activity/ activities they had the most difficulty with is shown in table 7.

Table 7. Percentage distribution of the daily activities that participants have the most difficulty (n=31)

Daily Activities	Difficult	Not Difficult
Preparing meals	48,4	51,6
Getting dressed	-	100,0
Doing laundry	64,5	35,5
Using the Toilet	12,9	87,1
Taking a Bath	32,3	67,7

The most stated difficulty is highlighted.

According to the results, 48.4% of the respondents stated that they had difficulty in preparing meals, 64.5% of the respondents stated that they had difficulty in doing laundry, 12.9% of the respondents stated that they had difficulty in using the toilet and 32.3% of the respondents stated that they had difficulty in taking a bath.

However, none of the participants stated the dressing activity among the activities they had difficulty (see Table 7). According to the results, it can be stated that among these activities, doing laundry is the most stated difficulty, while getting dressed is the least.

To analyze whether the results of people who did not use mobility devices change, their results were also analyzed separately (see Table 8).

Table 8. Percentage distribution of the responses to the questions about difficulty levels (n=5)

Daily Activities	1	2	3	4	5	Mean ($\bar{x}$)	SD (σ)
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
I have difficulty preparing meals.	20	0,0	60	20	0,0	2,80	1,09
I have difficulty getting dressed.	20	0,0	60	20	0,0	2,80	1,09
I have difficulty doing laundry.	0,0	0,0	60	20	20	3,60	0,89
I have difficulty using the toilet.	20	20	40	0,0	20	2,80	1,48
I have difficulty having a bath.	20	0,0	40	40	0,0	3,00	1,22

It is seen that to the statement “I have difficulty preparing meals” 20% of the respondents disagree, 60% of the respondents neutral and 20% of the respondents agree. To the statement “I have difficulty getting dressed”, 20% of the respondents disagree, 60% of the respondents neutral and 20% of the respondents agree. To the statement “I have difficulty doing laundry”, 60% of the respondents neutral, while 40% of the respondents agree. To the statement “I have difficulty using the toilet”, 40% of the respondents disagree, 40% of the respondents neutral and 20% of the respondents agree. To the statement of “I have difficulty having a bath”, 20% of the respondents disagree, 40% of the respondents neutral and 40% of the respondents agree (see Table 8).

Considering the mean values of the difficulties while doing daily activities, it can be stated that doing laundry is the most difficult activity with the highest mean value for the participants who don't use mobility devices.

The results obtained from the question (Q15) in which participants (for participants who don't use mobility devices) were asked to indicate the activity/ activities they had the most difficulty with is shown in table 9.

Table 9. Percentage distribution of the daily activities that participants have the most difficulty (n=5)

Daily Activities	Difficult	Not Difficult
Preparing meals	40	60
Getting dressed	0,0	100,0
Doing laundry	40	60
Using the Toilet	0,0	100,0
Taking a Bath	20	80

According to the results of participants who don't use mobility devices, 40% of the respondents stated that they had difficulty in preparing meals, 40% of the respondents stated that they had difficulty in doing laundry and 20% of the respondents stated that they had difficulty in taking a bath. However, none of the participants stated the dressing and using the toilet activities among the activities they had difficulty (see Table 9).

5.1.1.4. Level of Dependence For Each Activity and Related

Emotions

The results of level of dependence for each activity and related emotions were formed from answers of question 24 belonging to the *independency questions* in the survey (see Table 10). The aim of these results was to examine RQ2.

Table 10. Percentage distribution of the responses to the level of dependence and related emotions (n=31)

		1	2	3	4	5		
Daily Activities		Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Mean ($\bar{x}$)	SD (σ)
Level of Dependence	I feel dependent on someone while preparing meal.	16,1	12,9	19,4	32,3	19,4	3,26	1,37
	I feel dependent on someone while getting dressed.	58,1	19,4	9,7	9,7	3,2	1,81	1,17
	I feel dependent on someone while doing laundry.	9,7	3,2	25,8	25,8	35,5	3,74	1,26
	I feel dependent on someone while using the toilet.	54,8	16,1	6,5	6,5	16,1	2,13	1,54
	I feel dependent on someone while taking a bath.	38,7	19,4	6,5	9,7	25,8	2,65	1,68
Emerg Ed Emotions	It makes me feel comfortable to have someone help with daily activities.	48,4	16,1	6,5	19,4	9,7	2,26	1,48
	It makes me feel unhappy to have someone help with daily activities.	6,5	9,7	6,5	38,7	38,7	3,94	1,21
	It makes me feel guilty to have someone help with daily activities.	35,5	19,4	19,4	16,1	9,7	2,45	1,39

The activity that people are most dependent on, and the emotion most frequently felt as a result of dependency are shown highlighted.

To the statement “I feel dependent on someone while preparing meals”, 29% of the respondents gave the answer of disagree, 19,4% neutral, 51,7% agree. To the statement “I feel dependent on someone while getting dressed.”, 77,5% of the respondents gave the answer of disagree, 9,7% neutral, 12,9% agree. To the statement “I feel dependent on someone while doing laundry”, 12,9% of the respondents gave the answer of disagree, 25,8% neutral, 61,3% agree. To the statement “I feel dependent on someone while using the toilet”, 70,9% of the respondents gave the answer of disagree, 6,5% neutral, 22,6% agree. To the statement “I feel dependent on someone while having a bath”, 58,1% of the respondents gave the answer of disagree, 6,5% neutral, 35,5% agree. To the statement “It makes me feel comfortable to have someone help with daily activities”, 64,9% of the respondents gave the answer of disagree, 6,5% neutral, 29,1% agree. To the statement “It makes me feel unhappy to have someone help with daily activities”, 16,2% of the respondents gave the answer of disagree, 6,5% neutral, 77,4% agree. To the statement “It makes me feel guilty to have someone help with daily activities”, 54,9% of the respondents gave the answer of disagree, 19,4% neutral, 52,8% agree (see Table 10).

According to the distributions of the Answers to the Statements About *Level of Dependence*, the activity that people feel most dependent on someone is doing laundry with the mean value of 3,74. On the other hand, getting dressed and then using the toilet are the activities that the participants feel more independent.

According to the frequency of the feelings, it can be stated that the most common emotion when the young with mobility difficulties get help from someone while doing their daily activities is the feeling of being unhappy with the mean value of 3,94.

The results obtained from the question (Q25) in which participants were asked to indicate the activity/ activities they feel the most dependent on someone is shown in table 11.

Table 11. Percentage distribution of daily activities in which participants feel the most dependent on others (n=31)

Daily Activities	Dependent	Not Dependent
Preparing meals	58,1	41,9
Getting Dressed	9,7	90,3
Doing Laundry	74,2	25,8
Using the Toilet	19,4	80,6
Taking a Bath	32,3	67,7

The activity that is said the participants are most dependent to is highlighted.

According to the results, it is found that 58.1% of the respondents feel dependent on someone while preparing food, 9.7% while dressing, 74.2% doing laundry, 19.4% using the toilet and 32.3% while taking a bath (see Table 11). According to the results, it can be stated that doing laundry is the most stated activity that participants feel the most dependent.

To analyze whether the results of people who did not use mobility devices change, their results were also analyzed separately (see Table 12).

Table 12. Percentage distribution of the responses to the level of dependence and related emotions (n=5)

		1	2	3	4	5		
Daily Activities		Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Mean ($\bar{x}$)	SD (σ)
Level of Dependence	I feel dependent on someone while preparing meal.	20	0,0	60	20	0,0	2,80	1,09
	I feel dependent on someone while getting dressed.	40	0,0	20	20	20	2,80	1,78
	I feel dependent on someone while doing laundry.	0,0	0,0	60	20	20	3,60	0,89
	I feel dependent on someone while using the toilet.	40	0,0	20	20	20	2,80	1,78
	I feel dependent on someone while taking a bath.	40	0,0	20	20	20	2,80	1,78
Emerged Emotions	It makes me feel comfortable to have someone help with daily activities.	40	0,0	20	20	20	2,80	1,78
	It makes me feel unhappy to have someone help with daily activities.	0,0	0,0	20	20	60	4,40	0,89
	It makes me feel guilty to have someone help with daily activities.	40	0,0	20	20	20	2,80	1,78

It is seen that to the statement “I feel dependent on someone while preparing meal” 20% of the respondents disagree, 60% of the respondents neutral and 20% of the respondents agree. To the statement “I feel dependent on someone while getting

dressed”, 40% of the respondents disagree, 20% of the respondents neutral and 40% of the respondents agree. To the statement “I feel dependent on someone while doing laundry”, 60% of the respondents neutral, while 40% of the respondents agree. To the statement “I feel dependent on someone while using the toilet”, 40% of the respondents disagree, 20% of the respondents neutral and 40% of the respondents agree. To the statement of “I feel dependent on someone while taking a bath”, 40% of the respondents disagree, 20% of the respondents neutral and 40% of the respondents agree.

To the statement “It makes me feel comfortable to have someone help with daily activities”, 40% of the respondents disagree, 20% of the respondents neutral and 40% of the respondents agree. To the statement “It makes me feel unhappy to have someone help with daily activities”, 20% of the respondents neutral, while 80% of the respondents agree. To the statement, “It makes me feel guilty to have someone help with daily activities”, 40% of the respondents disagree, 20% of the respondents neutral and 40% of the respondents agree (see Table 12).

Considering the mean values of the dependency levels while doing daily activities, it can be stated that the activity that people who do not use mobility devices feel most dependent on is doing laundry with the mean value of 3,60. Also, considering the emotions that are emerged because of being dependent, feeling unhappy is the most stated emotion with the mean value of 4,40.

The results obtained from the question (Q25) in which participants (for participants who don't use mobility devices) were asked to indicate the activity/ activities they feel the most dependent on someone is shown in table 13.

Table 13. Percentage distribution of daily activities in which participants feel the most dependent on others (n=5)

Daily Activities	Dependent	Not Dependent
Preparing meals	20	80
Getting Dressed	40	60
Doing Laundry	60	40
Using the Toilet	20	80
Taking a Bath	40	60

When the participants who do not use mobility devices are considered separately in the question asking about the activities that the participants feel dependent, 20% of the respondents stated that they are dependent while preparing meals, 40% of the respondents stated that they are dependent while doing laundry and 60% of the respondents stated that they are dependent while doing laundry, 20% of the respondents stated that they are dependent while using the toilet and 40% of the respondents stated that they are dependent while taking a bath (see Table 13).

5.1.1.5. The Importance Levels That Participants give to the Daily Living Activities

The results of the importance levels that participants give to the daily living activities were formed from answers of question 28 belonging to the importance questions in the survey (see Table 14). The aim of these results was to examine RQ3.

Table 14. Percentage distribution of the responses to the questions about the importance levels (n=31)

	1	2	3	4	5		
Daily Activities	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Mean ($\bar{x}$)	SD (σ)
It is important to be able to prepare meals on my own	0,0	12,9	22,6	9,7	54,8	4,06	1,15
It is important to be able to get dressed on my own	0,0	0,0	9,7	6,5	83,9	4,74	0,63
It is important to be able to do laundry my own	22,6	19,4	9,7	9,7	38,7	3,23	1,67
It is important to be able to use the toilet on my own	3,2	0,0	9,7	3,2	83,9	4,65	0,92
It is important to be able to having a bath on my own	0,0	0,0	9,7	6,5	83,9	4,74	0,63

The activities with the highest mean value (the activities that people give the most important) are highlighted.

To the statement “It is important to be able to prepare meals on my own”, 12,9% of the respondents gave the answer disagree, 22,6% neutral, 64,5% agree. To the statement “It is important to be able to getting dressed on my own”, 9,7% of the respondents gave the answer neutral, 90,4% agree. To the statement “It is important to be able to doing laundry on my own”, 42% of the respondents gave the answer of

disagree, 9,7% neutral, 45,4%. To the statement “It is important to be able to using the toilet on my own”, 3,2% of the respondents gave the answer of disagree, 9,7% neutral, 87,1% agree. To the statement “It is important to be able to having a bath on my own”, 9,7% of the respondents gave the answer neutral, 90,4% agree (see Table 14).

Considering the mean values of the importance levels giving to the activities by the participants, getting dressed and having a bath is the most important activities for the participants with the mean value of 4,74. Also, using the toilet is the third important activity for the participants with the mean value of 4,65.

The results obtained from the question (Q29) in which participants were asked to indicate the activity/ activities they give more importance to is shown in table 15.

Table 15. Percentage distribution of daily activities that participants give the most importance (n=31)

Daily activities	Important	Not Important
The importance of being able to prepare meals	45,2	54,8
The importance of being able to get dressed	77,4	22,6
The importance of being able to do laundry	19,4	80,6
The importance of being able to use the toilet	80,6	19,4
The importance of being able to take a bath	87,1	12,9

The activities that are most important for the participants are highlighted.

According to the data obtained from the question in which participants were asked to indicate the activity/ activities they give more importance to, 45.2% of the participants stated that being able to prepare meals, 77.4% to be able to get dressed, 19.4% to be able to do laundry, 80.6% to be able to use the toilet, 87.1% to be able to take a bath are the most important activities to do on their own. This results indicates that while the participants consider having a bath, using the toilet and getting dressed as the most important activity, they consider doing laundry as the least important activity to do on their own (see Table 15).

To analyze whether the results of people who did not use mobility devices change, their results were also analyzed separately (see Table 16).

Table 16. Percentage distribution of the to the questions about the importance levels (n=5)

Daily Activities	1	2	3	4	5	Mean ($\bar{x}$)	SD (σ)
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree		
It is important to be able to prepare meals on my own	0,0	0,0	40	20	40	4,00	1,00
It is important to be able to get dressed on my own	0,0	0,0	40	20	40	4,00	1,00
It is important to be able to do laundry my own	0,0	0,0	40	20	40	4,00	1,00
It is important to be able to use the toilet on my own	0,0	0,0	40	20	40	4,00	1,00
It is important to be able to having a bath on my own	0,0	0,0	40	20	40	4,00	1,00

When the importance levels of daily activities giving by the 5 participants who do not use mobility devices were considered separately, it was seen that to the statement “It is important to be able to prepare meals on my own” 40% of the respondents neutral and 60% of the respondents agree. To the statement “It is important to be able to get dressed on my own”, 40% of the respondents neutral and 60% of the respondents agree. To the statement “It is important to be able to do laundry my own”, 40% of the respondents neutral, while 60% of the respondents agree. To the statement “It is important to be able to use the toilet on my own”, 40% of the respondents neutral and 60% of the respondents agree. To the statement of “It is important to be able to having a bath on my own”, 40% of the respondents neutral and 60% of the respondents agree (see Table 16).

Considering the mean values of the importance levels of daily activities, it can be stated that the participants who don't use mobility devices give importance to all activities equally.

The results obtained from the question (Q29) in which participants (for participants who don't use mobility devices) were asked to indicate the activity/ activities they give more importance to is shown in table 17.

Table 17. Percentage distribution of daily activities that participants give the most importance (n=5)

Daily activities	Important	Not Important
The importance of being able to prepare meals	60	40
The importance of being able to get dressed	80	20
The importance of being able to do laundry	40	60
The importance of being able to use the toilet	100	0,0
The importance of being able to take a bath	100	0,0

When the participants who do not use mobility devices are considered separately in the question asking about the activities that the participants give the most importance, 60% of the respondents stated that preparing meals is important, 80% of the respondents stated that getting dressed is important, 40% of the respondents stated doing laundry is important, 100% of the respondents stated that using the toilet is important and 100% of the respondents stated that taking a bath is important (see Table 17).

5.1.2. Correlation Analysis among Bodily Difficulties and Difficulties in Doing Daily Activities

The correlation among *the difficulties experienced by participants in terms of their capabilities and difficulties experiencing in the daily activities* were tested to examine RQ4 and H1. In this analysis, independent variable is the difficulties experienced by participants in terms of their capabilities, while dependent variable is the difficulties experiencing in the daily activities. Table 18 represents the correlations between these difficulties.

Table 18. Correlations among bodily difficulties and difficulties in doing daily activities

		using the arms	using the hands	using the legs	holding/using objects	using wheelchair/crutches	moving around without any assistance
Difficulty in preparing meals	r	,388*	,355*	,485**	,267	,115	,309
	p	,031	,049	,006	,146	,574	,091
Difficulty in getting dressed	r	,188	,163	-,006	,320	,672**	,565**
	p	,312	,382	,977	,080	,000	,001
Difficulty in doing laundry	r	,160	,385*	,401*	,235	-,341	-,111
	p	,391	,032	,025	,203	,089	,554
Difficulty in using the toilet	r	,313	,322	,135	,389*	,630**	,586**
	p	,086	,077	,467	,031	,001	,001
Difficulty in taking a bath	r	,258	,593**	,380*	,668**	,422*	,446*
	p	,161	,000	,035	,000	,032	,012

The correlations are highlighted. **p<0,01; *p<0,05

5.1.2.1. Arms

The results show that for the correlation between difficulty in using the arms and difficulty in preparing meals, Spearman's $r=0,388$ so there is a positive moderate association between difficulty in using the arms and difficulty in preparing meals ($p<0,05$). On the other hand, it is found that there is no significant relationship between having difficulty in using the arms and having difficulty while dressing, doing laundry, using the toilet and having a bath ($p>0,05$) (see Table 18).

Therefore, it can be stated that the greater the difficulty in using the arms, the greater the difficulty in preparing meals. However, it cannot be stated that the difficulties experienced while dressing, doing laundry, using the toilet and having a bath will increase with the increase in the difficulty experienced in the arms. In this context, it can be inferred that the difficulties in the arms mostly affect the activities of preparing meals.

5.1.2.2. Hands

The results show that for the correlation between difficulty in using the hands and difficulty in preparing meals, Spearman's $r=0,355$ so there is a positive moderate association between difficulty in using the hands and difficulty in preparing meals ($p<0,05$). In addition, it is found that there is a positive moderate association between difficulty in using the hands and difficulty in doing laundry ($r= 0,385$, $p<0,05$).

Furthermore, there is a positive moderate association between difficulty in using the hands and difficulty in having a bath ($r=0,593$, $p<0,01$). On the other hand, it is found that there is no significant relationship between having difficulty in using the hands and using the toilet. Also, there is no significant relationship between having

difficulty in using the hands and having difficulty while getting dressed ($p>0,05$) (see Table 18).

Therefore, it can be stated that the greater the difficulty in using the hands, the greater the difficulty in preparing meals, doing laundry and having a bath. However, it cannot be stated that the difficulties experienced while dressing or using the toilet will increase with the increase in the difficulty experienced in the hands. In this context, it can be inferred that the difficulties in the hands mostly affect the activities of preparing meals, doing laundry and having a bath.

5.1.2.3. Legs

The results show that for the correlation between difficulty in using the legs and difficulty in preparing meals, Spearman's $r=0,485$ so there is a positive moderate association between difficulty in using the legs and difficulty in preparing meals ($p<0,01$). Also, there is a positive moderate association between difficulty in using the legs and doing laundry ($r=0,401$, $p<0,05$) and there is a positive moderate association between difficulty in using the legs and having a bath ($r=0,380$, $p<0,05$). On the other hand, it is found that there is no significant relationship between having difficulty in using the legs and having difficulty while getting dressed and using the toilet and ($p>0,05$) (see Table 18).

Therefore, it can be stated that the greater the difficulty in using the legs, the greater the difficulty in preparing meals, doing laundry and having a bath. However, it cannot be stated that the difficulties experienced while getting dressed and using the toilet will increase with the increase in the difficulty experienced in the legs. In this context, it can be inferred that the difficulties in the legs mostly affect the activity of preparing meals, doing laundry and having a bath.

5.1.2.4. Holding/using objects

The results show that for the correlation between difficulty in holding/using objects and difficulty in using the toilet, Spearman's $r=0,389$ so there is a positive moderate association between difficulty in holding/using the objects and difficulty in using the toilet ($p<0,05$). Also, there is a positive moderate association between difficulty in holding/using the objects and difficulty having a bath ($r=0,668$, $p<0,01$). On the other hand, it is found that there is no significant relationship between having difficulty in holding/using the objects and having difficulty while preparing meals, getting dressed and doing laundry ($p>0,05$) (see Table 18).

Therefore, it can be stated that the greater the difficulty in holding/using the objects, the greater the difficulty in using the toilet and having a bath. However, it cannot be stated that the difficulties experienced while preparing meals, doing laundry and getting dressed will increase with the increase in the difficulty experienced in holding/using the objects. In this context, according to the results of the associations, it can be inferred that the difficulties in holding/using the objects mostly affect the difficulties in having a bath. After having a bath, using the toilet is affected by the difficulties in holding/using objects.

5.1.2.5. Using Wheelchair/Crutches

The results show that for the correlation between difficulty in using wheelchair/crutches and difficulty in getting dressed, Spearman's $r=0,672$ so there is a positive moderate association between difficulty in using wheelchair/crutches and difficulty in getting dressed ($p<0,01$). Also, there is a positive moderate association between difficulty in using wheelchair/crutches and difficulty in using the toilet ($r=0,630$, $p<0,01$) and difficulty in using wheelchair/crutches and difficulty in having

a bath ($r=0,422$, $p<0,05$). On the other hand, it is found that there is no significant relationship between having difficulty in using wheelchair/crutches and having difficulty while preparing meals and doing laundry ($p>0,05$) (see Table 18).

Therefore, it can be stated that getting dressed, using the toilet and having a bath are the activities that are affected by the having difficulty in using wheelchair/crutches.

5.1.2.6. Moving Around without any Assistance

The results show that for the correlation between difficulty in moving around without any assistance and difficulty in getting dressed, Spearman's $r=0,565$ so there is a positive moderate association between difficulty in moving around without any assistance and difficulty in preparing meals ($p<0,01$). Also, there is a positive moderate association between difficulty in moving around without any assistance and difficulty in using the toilet ($r=0,586$, $p<0,01$). In addition, there is a positive moderate association between difficulty in moving around without any assistance and difficulty in having a bath ($r=0,446$, $p<0,05$). On the other hand, it is found that there is no significant relationship between having difficulty in moving around without any assistance and having difficulty while preparing meals and doing laundry ($p>0,05$) (see Table 18).

Therefore, it can be stated that getting dressed, using the toilet and having a bath are positively affected by the having difficulty in moving around without any assistance.

Considering these results, H1 is verified that there is a positive correlation between the difficulties young people with CP experience in their bodies and the difficulties they experience in the activities. However, the correlation between the difficulties people experience in different parts of their bodies and the difficulties they

experience in activities varies. For instance, while difficulty in using the arms is only correlated with difficulty in preparing meals, difficulty in using the hands is correlated with difficulty in preparing meals, difficulty in doing laundry and difficulty in taking a bath.

5.1.3. Correlation Analysis among the Difficulties in Doing Daily Activities and Level of Dependence

The correlation among *the difficulties in doing daily activities and level of dependence* were tested to examine RQ5 and H2. In this analysis, independent variable is the difficulties in doing daily activities, while dependent variable is the level of dependence while doing daily activities. Table 19 represents the correlations among these difficulties.

Table 19. Correlations among the difficulties experienced by the participants while doing daily activities and their level of dependence

		Level of Dependence
Difficulty in preparing meals	r	,741**
	p	,000
Difficulty in getting dressed	r	,718**
	p	,000
Difficulty in doing laundry	r	,609**
	p	,000
Difficulty in using the toilet	r	,799**
	p	,000
Difficulty in Taking a Bath	r	,869**
	p	,000

The correlations are highlighted. **p<0,01; *p<0,05

The results show that for the correlation between difficulty in preparing meals and level of dependence during preparing meals, Spearman's $r=0,741$ so there is a positive high association between difficulty in preparing meals and level of dependence during preparing meals ($p<0,01$) (see Table 19). Therefore, it can be stated that according to the participants in this study, as the difficulties experienced by people while preparing meals increase, their level of dependence also increases.

The results show that for the correlation between difficulty in getting dressed and level of dependence during getting dressed, Spearman's $r=0,718$ so there is a positive high association between difficulty in getting dressed and level of dependence during getting dressed ($p<0,01$) (see Table 19). Therefore, it can be stated that according to the participants in this study, as the difficulties experienced by people while getting dressed increase, the level of dependence on someone also increases.

The results show that for the correlation between difficulty in doing laundry and level of dependence during doing laundry, Spearman's $r=0,609$ so there is a positive moderate association between difficulty in doing laundry and level of dependence during doing laundry ($p<0,01$) (see Table 19). Therefore, it can be stated that according to the participants in this study, as the difficulties experienced by people while doing laundry increase, the level of dependence on someone also increases.

The results show that for the correlation between difficulty in using the toilet and level of dependence during using the toilet, Spearman's $r=0,799$ so there is a positive high association between difficulty in using the toilet and level of dependence during using the toilet ($p<0,01$) (see Table 19). Therefore, it can be stated that according to the participants in this study, as the difficulties experienced by people while using the toilet increase, the level of dependence on someone also increases.

The results show that for the correlation between difficulty in having a bath and level of dependence during having a bath, Spearman's $r=0,869$ so there is a positive high association between difficulty in having a bath and level of dependence during having a bath ($p<0,01$) (see Table 19). Therefore, it can be stated that according to the participants in this study, as the difficulties experienced by people while having a bath increase, the level of dependence on someone also increases.

According to these correlations among *the difficulties in doing daily Activities and the level of dependence*, it can be stated that as the difficulties increase while doing the daily activities, the level of dependence on other people increases.

Considering these results, H2 is verified that there is a positive correlation between the difficulties young people with cerebral palsy experience while doing daily activities and their level of dependence.

5.1.4. Correlation Analysis among the Difficulties Experienced by the Participants while Doing Daily Activities and the Importance Levels Given to the Activities

The correlation among *the difficulties in doing daily activities and importance levels giving to the daily activities* were tested to examine RQ6 and H3. In this analysis, independent variable is the difficulties in doing daily activities, while dependent variable is the importance levels giving to the doing daily activities. Table 20 represents the correlations among these difficulties.

Table 20. Correlations among the difficulties experienced by the participants while doing daily activities and importance levels giving to the activities

		Importance Levels
Difficulty in preparing meals	r	-,270
	p	,142
Difficulty in getting dressed	r	-,562**
	p	,001
Difficulty in doing laundry	r	-,218
	p	,238
Difficulty in using the toilet	r	-,359
	p	,236
Difficulty in taking a bath	r	-,226
	p	,221

The only correlation is highlighted. ** $p < 0,01$; * $p < 0,05$

The results indicate that for the correlation between difficulty in getting dressed and importance of getting dressed on their own, Spearman's $r = -0,562$ so there is a negative moderate association between difficulty in getting dressed and importance of getting dressed on their own ($p < 0,01$) (see Table 20).

The results show that there is no significant relationship between difficulty in preparing meals, doing laundry, using the toilet and taking a bath and the importance of doing these activities on their own ($p > 0,05$) (see Table 20).

Considering these results, H3 is rejected that there is no positive correlations between the difficulties young people with CP experience while doing daily activities and the importance level they give to the activities. There is only a negative correlation between the difficulty in getting dressed and importance that is given to getting

dressed. Therefore, it means that when the difficulty in getting dressed increases, the importance given to getting dressed decreases.

5.1.5. Correlation Analysis Among the Level of Dependence while Doing Daily Activities and The Importance Levels Given to the Activities

The correlation among *the level of dependence while doing daily activities and the importance levels giving to the daily activities* were tested to examine RQ7 and H4.

In this analysis, independent variable is the level of dependence while doing daily activities, while dependent variable is the importance levels giving to the daily activities. Table 21 represents the correlations among these difficulties.

Table 21. Correlations among the level of dependence while doing daily activities and importance levels giving to the activities

		Importance Levels
Level of dependence while preparing meals	r	-,413*
	p	,021
Level of dependence while getting dressed	r	-,665**
	p	,000
Level of dependence while doing laundry	r	-,417*
	p	,019
Level of dependence while using the toilet	r	-,350
	p	,053
Level of dependence while taking a bath	r	-,311
	p	,088

The correlations are highlighted. **p<0,01; *p<0,05

The results indicate that for the correlation between the level of dependence while preparing meals and importance giving to preparing meals on their own, Spearman's $r = -0,413$ so there is a negative moderate association between the level of dependence while preparing meals and importance giving to preparing meals on their own ($p < 0,05$) (see Table 21). Therefore, it can be stated that the more the participants feel dependent on someone while preparing meals, the less importance they give to preparing meals on their own.

The results show that for the correlation between the level of dependence while getting dressed and importance giving to getting dressed on their own, Spearman's $r = -0,665$ so there is a negative moderate association between level of dependence while getting dressed and importance giving to getting dressed on their own ($p < 0,01$) (see Table 21). Therefore, it can be stated that the more the participants feel dependent on someone while getting dressed, the less importance they give to getting dressed on their own.

The results show that for the correlation between level of dependence while doing laundry and importance giving to doing laundry on their own, Spearman's $r = -0,417$ so there is a negative moderate association between level of dependence while doing laundry and importance giving to doing laundry on their own ($p < 0,05$) (see Table 21). Therefore, it can be stated that the more the participants feel dependent on someone while doing laundry, the less importance they give to doing laundry on their own.

The results show that there is no significant relationship between the level of dependence while using the toilet and importance giving to using the toilet on their own and the level of dependence while taking a bath and the importance giving to having a bath on their own and ($p > 0,05$) (see Table 21).

According to the correlations among *the level of dependence while doing daily activities and the importance levels giving to the activities*, it can be stated that the importance that participants give to preparing meals, getting dressed and doing laundry on their own is negatively related to the level of dependence.

Considering these results, H4 is rejected that there is no positive correlations between the level of dependence of young people with CP and the importance level they give to the activities. There is only a negative correlation between importance that participants give to preparing meals, getting dressed and doing laundry on their own and level of dependence while doing these activities. This means that when the importance giving to preparing meals, getting dressed and doing laundry increase, the levels of dependence while doing these activities decrease.

5.2. Results of the Open-ended Survey Questions and the Interview

5.2.1. Analysis Procedure of the Open-ended Survey Questions and the Interview

This section includes insights obtained from open-ended survey questions and interviews. A total of ten people out of thirty one participants answered open-ended questions in the survey. Even if the answers were short, they were at a level that could give enough information about the difficulties people experienced, their feelings and the adaptations they made or wish to make in their homes.

The people who participated in the interview were selected from the people who participated in the survey before. The mothers participating in the interview are the mothers of the young people who participated in the survey (see Table 22). While creating the content analysis tables, the people who participated in both the survey and the interviews are shown in the interviews participation section.

Table 22. Demographic characteristics and survey participation numbers of the interview participants

		Age	Mobility Device	Survey Participation Number
Young people with cerebral palsy	P1	21	No device	R18
	P2	24	Crutches	R20
	P3	24	Crutches	R25
	P4	28	Wheelchair	R28
Mothers	P5	52(child: 18)	Wheelchair	R30
	P6	54(child: 24)	Wheelchair	R31

After the interview with six different participants, different perspectives were gained from young people with cerebral palsy and the difficulties they experienced. The fact that four of the interviewees are young people with cerebral palsy who have different mobility levels increased the diversity of the study and broadened the perspectives about cerebral palsy. While the first participant does not use any mobility device, the second and third use crutches and the fourth use a wheelchair. In addition, the two mothers who participated in the interview are people who have children with cerebral palsy who are wheelchair users (see Table 22). They brought a different perspective to the study in terms of being a parent.

In this study, in order to analyze the qualitative data, firstly, the responses of the participants were analyzed. Because it is important to specify the themes for the study (Williams, 2007), a content analysis method was applied. Carrying out content analysis is an effective way to analyze qualitative data (White & Marsh, 2006). Among the approaches to content analysis, firstly, a deductive research approach was used to determine the main themes. Then, an inductive research approach was applied to create sub-themes because in the inductive research approach, theories are created after data is collected (White & Marsh, 2006). After specifying the themes for this study, as recommended by Mayring (2004), some sub-themes were created based on the answers to open-ended survey questions and the interviews to analyze the data in detail.

Firstly, considering the research questions, three main themes were determined including *reasons of not performing activities in the homes, level of dependence and related emotions, and the adaptations in the homes*. After evaluating the responses in both phases, some sub-themes were determined (see Table 23).

Table 23. Themes and sub-themes

	THEMES							
	Reasons of not Performing Activities			Level of Dependence& Related Emotions			Adaptations	
SUB-THEMES	Low body dexterity	Physical Barrier	Others do/ Not preferred	Unhappiness	Anger	Guilt	Applied	Wished

5.2.2. Reasons of not Performing Activities

In line with the answers from the participants, it was determined that not performing activities at home are based on three main reasons: low body dexterity, physical barriers and others do/not preferred. After examining the open-ended questions of the survey and the answers to the interview, the answers to the reasons of not performing activities were distributed to the appropriate ones from these sub-themes (see Table 24). Considering the sub-themes, *low body dexterity* refers the difficulties that are caused by the inabilities that the participants have in their bodies. The sub-theme of *physical barriers* refers to the difficulties that are caused because of the obstacles that are encountered in the environment. Also, *others do/not preferred* refers to the answers of people who do not do the activities because others do it or because they do not prefer to do it themselves.

Table 24. Distribution of the reasons of not performing activities according to sub-themes

Activities	Low Body Dexterity			Physical Barrier			Others Do/ Not Preferred		
	S	I	T	S	I	T	S	I	T
Preparing meals	4	1	5	5	1	6	4	-	4
Getting dressed	2	2	4	1	1	2	-	-	-
Doing laundry	6	-	6	2	1	3	6	1	7
Using the toilet&sink	2	2	4	2	3	5	-	-	-
Having a bath	2	-	2	6	2	8	-	-	-
Circulation	-	-	-	1	5	6	-	-	-

S: Responses to open-ended survey questions; I: Responses to interview; T: Total number of responses

When the open-ended questions of the survey and the answers to the interview were examined, it is determined that six participants can not prepare meals, four participants can not get dressed, six participants cannot do laundry, four participants cannot use the toilet and sink, and two participants can not take a bath due to *low body dexterity*.

Considering the activity of preparing meals, the statement below can be an example:

“I can't use my hands actively so it's hard to hold things”.

Considering the activity of getting dressed, the statement below can be an example:

“It's just hard for me to wear socks, pants and shoes, but I can still do them, it just takes a little time”.

Considering the activity of doing laundry, the statement below can be an example:

“I can't carry heavy as my hands are weak. Therefore, I cannot remove the laundry basket”.

When the open-ended questions of the survey and the answers to the interview were examined, it is determined that six participants can not prepare meals, two participants can not get dressed, three participants can not do laundry, five participants can not use the toilet and sink, eight participants can not take a bath and six participants can not do circulation due to *physical barriers*.

Considering the activity of preparing meals, the statement below can be an example:

“The counter is too high. Also, since the wheelchair doesn't go under the counter, I don't have any access at all”.

Considering the circulation in the homes, the statements below can be examples:

“One of the things they have the most difficulty with is the slippery floors, they are not suitable for them. Even if my son has special shoes on his feet, he slips a lot when walking on hardwood or stone floors”.

“I only pay attention to the corners because I can lose my balance on sharp turns. And of course, the door sills are the most challenging thing for me in the home”.

When the open-ended questions of the survey and the answers to the interview were examined, it is determined that four participants do not prepare meals and seven participants do not do laundry because *others do or because they do not prefer to do*.

Considering the activity of preparing meals, the statement below can be an example:

“I don't like to prepare food so I don't”.

Considering the activity of doing laundry, the statement below can be an example:

“My mom always does the laundry so I don't need it”.

5.2.3. Level of Dependence and Related Emotions

In line with the answers from the participants, it is determined that the emotions that young people with cerebral palsy felt when they received help from others at home were related to three basic emotions: *unhappiness, anger, guilt*. After examining the open-ended questions of the survey and the answers to the interview, the answers to the emotions they felt when they received help from others while doing the activities were distributed to the appropriate ones from these sub-themes (see Table 25).

Table 25. Distribution of the emotions

Emotions	Unhappiness			Anger			Guilt		
	S	I	T	S	I	T	S	I	T
	6	2	8	1	1	2	3	1	4

S: Responses to open-ended survey questions; I: Responses to interview; T: Total number of responses

When the open-ended questions of the survey and the answers to the interview were examined, it is determined that eight participants felt the *emotion of unhappiness* when they received help from others while doing the activities. The statement below can be an example:

“I am not happy that my parents always want to help me. This winter I will be 25 years old and my father or mother is still helping me with walking and I am very unsatisfied with this”.

The results show that two participants felt the *emotion of anger* when they received help from others while doing the activities. The statement below can be an example:

“I don’t need any help. When someone helps me I get angry”.

The results indicate that four participants felt the *emotion of guilt* when they received help from others while doing the activities. The statement below can be an example:

“When I get help, I feel a little guilty just for getting in the way of other people’s work”.

5.2.4. Adaptations

In line with the answers from the participants, the adaptations that people found suitable for their homes after the difficulties they experienced in their homes were divided into two sub-themes: *applied* and *wished*. After examining the survey open-ended questions and the answers to the interview, the answers to the adaptations that people deem necessary for their homes were distributed to the appropriate ones from these sub-themes (see Table 26). In the table, it is indicated how many people have applied these adaptations and how many people want to apply them.

Table 26. Distribution of the adaptations in the homes according to sub-themes

Adaptations	Applied			Wished		
	S	I	T	S	I	T
Arranging kitchen shelves	-	-	-	6	1	7
Adding ramp	-	1	1	-	-	-
Using carpets	1	2	3	-	-	-
Installing grab bars	6	4	10	-	-	-
Changing the toilet style	-	1	1	-	-	-
Using shower cabinet	4	2	6	-	-	-
Using a low-sink	-	-	-	-	1	1
Adding a gym area	-	1	1	-	-	-

S: Responses to open-ended survey questions; I: Responses to interview; T: Total number of responses

With regards to *applied adaptations*, one participant added a ramp to the entrance of his house, three participants started using carpet at home, ten participants used grab bars in their toilets, one participant placed the Turkish style toilet in their home with a modern toilet, six participants started using a shower cabinet and one participant added a gym area to her home.

Considering the adaptation of using carpets, the statement below can be an example:

“Before that, we did not have carpet in the bathroom but now, we usually have carpet. Also, we had carpet installed in the rest of the home, so I slip less now”.

Considering changing the toilet style, the statement below can be an example:

“Our previous home had a Turkish style toilet. My father built a new style toilet so that I could be more comfortable”.

Considering the adaptation of adding a gym area, the statement below can be an example:

I made a gym area inside the home for their muscle development. First, I hung a rope on the ceiling with the dowel. Then I made a climbing track for them with the rolling pins I fixed (see Figure 3). In this way, they can do various movements to improve their muscles there.



Figure 3. The gym area made by the participant five

With regards to *wished adaptations*, seven participants wanted to make the kitchen cabinets in their homes suitable for their height, two participants wanted to add a ramp to their house and one participant wanted to reduce the height of the sink in the bathroom.

Considering the wish of arranging kitchen shelves, the statement below can be an example:

“Since I cannot access the cabinets in the kitchen, I would like to have the cabinets made according to my reach height, but I cannot do this because the making a renovation is too costly”.

Considering the wish of having lower sink in the bathroom, the statement below can be an example:

“I’m thinking of making a low sink to wash my head”.

During the interviews about adaptations, the part where people explained why they could not apply some adaptations they wanted at home was remarkable. Considering the reasons of why adaptations were not made, the statements below can be examples:

“Since I cannot access the cabinets in the kitchen, I would like to have the cabinets made according to my reach height, but I cannot because it is too costly”.

“We have been trying to solve every problem we encounter for years, but of course, the biggest obstacle is always financial difficulties”.



CHAPTER VI

DISCUSSION

In this study, it was predicted that young people with cerebral palsy experience varying difficulties while doing their daily activities due to their different mobility levels. Frequency analysis was used to analyze the *differences in difficulties experienced while performing the daily activities* (RQ1). According to the results of this frequency analysis, the activity that the largest percentage of people cannot do without assistance is doing laundry, while the activity that the smallest percentage of people cannot do without assistance is getting dressed. Consequently, it can be stated that people with cerebral palsy level 3 and 4 have the most difficulty while doing laundry and the least difficulty while getting dressed. However, on the other hand, according to the study conducted by Carmona-Torres et al. (2019), for wheelchair users, bathing is the most difficult activity, while dressing is the second most difficult activity. Also, according to the study conducted by Nieuwenhuijsen et al. (2009), preparing meals and getting dressed are the most common difficulties for young people with cerebral palsy. The level of difficulty people experience while doing activities may be due to differences in people's mobilities. In addition, the variety of mobility devices they use may also be a factor influencing this. Although in this study the participants were selected from people with cerebral palsy level 3 and 4, the fact that people with level 3 can develop themselves physically and can walk without using a mobility device may be one of the factors that cause the difficulty levels to change. However, there are also examples where the use of mobility devices

does not make a difference, as there is still difficulty in hand and foot controls even if they do not use a mobility device. For example, one of the people who did not use a mobility device stated that she/he had no difficulty using her hands, arms or feet and that she could do the activities without assistance. However, other participants who did not use mobility devices stated that even though they did not have difficulty in controlling their feet, they had difficulty in controlling their hands and arms and therefore had difficulty in all activities.

As a result of the literature review, it was predicted that people who have different mobility difficulties in their bodies will have different levels of difficulty in activities. As Steinfeld and Maisel (2012) emphasized, there are no specific rules to design accessible spaces because everybody has different difficulties in their bodies. Furthermore, as Seidel et al. (2011) stated, since the postures of the disabled exhibited during the activities differ, the daily activities should be examined in detail and the products and spaces should be arranged accordingly. Also, the ability of the people should be understood to evaluate the possible difficulties they may encounter with. Therefore, in order to understand the relationship between *the difficulties experiencing in the bodies and the difficulties experienced in the activities* (RQ4 and H1), Spearman's correlation coefficient test was used. According to the results, when the analyses are examined, it is understood that the difficulties people experience in activities are related to the difficulties they experience in the different parts of their bodies. Therefore, the Hypothesis 1 is verified that there is a positive correlation between the difficulties young people with CP experience in their bodies and the difficulties they experience in the activities. Accordingly, before the spaces are designed according to people, the difficulties they experience in their bodies and as a result, the difficulties they experience in activities should be taken into consideration.

According to the results of the study, the mobility of the people with cerebral palsy under the heading of *the difficulties in moving around without any assistance*, affects the difficulties in performing daily activities. Cook & Hussey (1995) pointed out that in order for people to perform their daily activities more comfortably, their mobility ought to be at a considerable level. Besides, as Imrie (2004), Routhier et al. (2003) and Hendy & Pascall (2001) emphasized, mobility difficulties encountered in the home environment due to architectural obstacles cause people to have difficulties while doing their daily activities. According to the results of this study, there is a positive moderate association between difficulty in moving around without any assistance and difficulty in getting dressed, using the toilet and having a bath (see Table 10). Consequently, difficulty in moving around without any assistance in the home environment causes young people with cerebral palsy to have difficulties while dressing, using the toilet and having a bath.

The results of the *level of dependence of the participants* (RQ2) indicate that the level of dependence that people have while performing different activities varies. Activity in which people feel the most dependent on someone is doing laundry, while the activity which people feel least dependent on someone is getting dressed. The results of the study indicate that the level of dependence of young people with cerebral palsy is related to the difficulties they experience while performing daily activities (RQ5 and H2). Therefore, Hypothesis 2 is verified that there is a positive correlation between the difficulties young people with cerebral palsy experience while doing daily activities and their level of dependence. According to these correlations, it can be stated that as the difficulties increase while doing the daily activities, the level of dependence on other people increases. It can be stated that when the difficulties they encounter in the home increase, they become feel less

independent. As Caesarendra et al., (2015) stated, when people's mobility is improved according to their daily activities, they begin to feel more independent. Also, as Petersson et al. (2012) emphasized, one of the main improvements that provide people who have mobility difficulties to feel more independent is having an accessible home that decreases difficulties they can encounter in the home.

After it was understood that there is a relationship between the difficulties people experience and their level of dependence, RQ7 and H4 were created to understand whether there is a relationship between people's dependence on activities and the importance given to those activities. According to the results, it was understood that being dependent on someone only for preparing meals, getting dressed and doing laundry activities was associated with the importance given to those activities, but this relationship was also negative. Therefore, H4 rejected.

Before analyzing the results of the survey, it was assumed that it would be concluded that people had concerns about getting help from others. This assumption was made because according to Kelly et al., (2016), people with mobility difficulties may experience feelings of worry, sadness, anger or guilt when they depend on others. Also, as Kabuta (2014) stated, disabled young people feel unhappy about being dependent on their parents. Similarly, according to the results of this study to understand *the emotions that emerged because of being dependent on others* (RQ2a), the most common emotion felt by people who get help from someone while doing daily activities was unhappiness. Furthermore, the feeling of unhappiness was the most common response, with the second and third participants among the participants in the interview saying that they felt unhappy when they get help from someone else. The feeling of unhappiness is followed by anger and guilt.

As a result of the analyses made to compare *the importance that young people with cerebral palsy give to daily activities (RQ3)*, the activity that people give the most importance to do on their own is being able to have a bath, while the least important activity to do on their own is being able to do laundry. As a similar result, according to the study conducted by Lemmens et al. (2014), getting dressed is the most important goal for the youngest people with cerebral palsy (aged between 2.5-11). Besides, preparing meals and personal hygiene including using the toilet and taking a bath are the most important goals for the oldest participants (aged between 12-20) (Lemmens et al., 2014). As can be seen, the level of importance that people attach to the activities varies. There may be different reasons for the differences. For instance, after the interview and open-ended survey questions, it was understood that many people do not attach importance to laundry or meal preparation activities because others in their families do it. Also, some participants mentioned in the interview and open-ended questions that they do not know how to cook or they don't like cooking and that's why they don't cook. As Hertig-Godeschalk et al. (2017) emphasized, some people don't care if their kitchen is accessible if there is someone cooking at home. Therefore, since the level of importance people attach to activities differs, designers should prioritize users' lifestyles and preferences when designing accessible spaces.

After seeing that the degree of importance that people attach to activities changed, it was mentioned that there could be different reasons. Before the analyzes, RQ7 and H3 were created to understand whether the importance given to the activities is related to the difficulties experienced in the activities. According to the results, only the difficulties experienced while getting dressed have a relationship with the

importance given to that activity and this relationship is negative. Therefore, H3 is rejected.

Considering the activities and spaces in more detail, beyond the survey results, according to the open-ended survey questions and interviews, the most difficult features for the participants of the interview at home are narrow spaces and the door sills, especially in the living rooms, and the slippery floors in the bathroom.

However, according to the study conducted by Norin et al. (2020), high cupboards and shelves were the most stated obstacles for the participants. In the interview of this study, high kitchen shelves were stated by only one participant. It is observed that the reasons of not performing daily activities varies including low body dexterity, physical barriers and others do/not preferred. However, it is concluded that the most important obstacles for participants, such as slippery floors and narrow areas, were not included in the survey. Besides, it is determined that the difficulties experienced by the people participating in the open-ended survey questions and interviews varied due to the different mobility levels. For instance, while young people with cerebral palsy who did not use any mobility device had the least difficulty, it was revealed that wheelchair users had the most problems. Therefore, the importance of cerebral palsy levels in people should be emphasized in order to understand the difficulties they experience in activities.

In the interview, according to the experiences of people over the years, *the adaptation they made and wish to make in their homes* (RQ2b) were evaluated.

According to the participants of the interview, using carpets, shower cabinets and grab bars in the bathroom are the most preferred adaptations in their homes.

However, according to the study conducted by Norin et al. (2020), while using ramps at the entrance is the most preferred adaptation, using lower kitchen cabinets in the

kitchen is the second, and using angle-adjustable washbasin, washbasin extended from wall and wall-mounted toilet armrests in the bathroom is the third most preferred adaptations in the homes. The reason why the participants mentioned less about the ramp and kitchen cabinets in the interview may be financial inadequacies. Considering the financial inadequacies that home owners can have, in order to provide more accessible living spaces for people with mobility difficulties, designers should consider accessible features at the first stage.



CHAPTER VII

CONCLUSION

In this study, the experiences of young people with cerebral palsy while doing their daily activities in home environments were analyzed. As a result of these experiences, the difficulties experienced by young people with cerebral palsy, their feelings of independence, their general feelings when they get help from others and the differences in the importance they attach to the daily activities were examined with frequency tables. The main purpose of these examinations was to analyze the daily activities separately and to reveal their differences.

According to the results, it is revealed that the difficulties people experience in activities vary. Also, these difficulties are related to the difficulties they experience in the different parts of their bodies. In addition, the importance levels that people with cerebral palsy give to the daily activities vary. The possible reasons for the differences were discussed in the previous chapter.

According to the results, as the difficulties while doing the daily activities increase, the level of dependence on other people increase. Namely, the level of independence is affected negatively by the difficulties that young with mobility difficulties experience in doing daily activities. Also, the difficulties experienced in getting dressed have a negative moderate association with the importance given to that activity.

According to the results, it can be stated that there is a negative relationship between the level of dependence while doing preparing meals, getting dressed and doing laundry with importance level giving to these activities.

In the interview, questions were asked in order to understand the difficulties experienced by young people with cerebral palsy in more detail. The information coming from the interview is important because responses to the survey were few and were not detailed.

After these analyses, some basic inferences were made and accordingly, some issues that should be addressed before designing accessible spaces are emphasized in the following section.

7.1. Implications of the Study on Interior Architecture

As a result of this research, it has been revealed that the difficulty levels of people while performing activities change. After both survey and interview analysis, it was understood that the devices they use should be taken into account, as the difficulties experienced by people may vary depending on their mobility level. However, as revealed in this study, even if people do not use mobility devices, they may have some difficulties in their bodies. According to the results of this study, there are relationships between the difficulties people experience in their bodies and the difficulties they experience while doing activities. For this reason, while designing accessible spaces, generalizations should be avoided and the difficulties experienced by people with the mobility device they use should be understood. Considering that the physical difficulties in their bodies affects the difficulties experienced while doing daily activities, it is hard to set rules to design spaces for people with mobility difficulties. Rather than applying any rules, after understanding the difficulties they have in their bodies, the most effective designs can be created.

As a result of the research, it has been revealed that the level of importance that people give to activities changes. It has been discussed in the previous chapter that there may be different reasons for this change. Because of these differences, designers should analyze the importance that users attach to activities in addition to the difficulties they experience while designing accessible spaces at the earlier stages of the design process.

According to the results of the open-ended survey questions and interviews, the participants mentioned additional activities such as doing circulation, addition to the daily activities mentioned in the survey. Therefore, in order to analyze the difficulties people experience at home, in addition to asking the basic activities included in BADL and IADL, activities should be considered in more detail. For this purpose, it will be useful to conduct a large-scale interview or add more specific activities in the survey.

Lastly, in the interview, in addition to the young people with cerebral palsy who perform the activities, the opinions of the parents were also taken. The views of the parents brought a deeper and different perspective to the study. For instance, when the adaptations people applied and wish to have in their homes are examined, especially according to parents, one of the most important issues when making arrangements in their homes is financial inadequacies. Therefore, when designing accessible spaces, it is important to get the opinions of people who help people, in addition to people who experience the spaces. Also, considering the adaptations that people cannot make due to their financial inadequacies, the accessible features should be made by the designers while designing the spaces.

7.2. Limitations of the Study and Future Research Areas

In this study, many certain limitations were encountered. Firstly, it was difficult to find studies in the literature on some specific topics such as studies evaluating and comparing the activities of children with cerebral palsy. Therefore, it was challenging to make inferences and discuss the issues with the studies in literature. In addition, it was aimed to start the survey earlier. However, when the ethics committee requested revision of the documents prepared for approval of the ethics committee, the beginning of the survey was extended. Furthermore, because the participation in the study requires very specific characteristics, finding the participants was also an issue. Therefore, the number of participants stayed below the expected number. The duration of the survey was also extended because the participation of the participants was delayed.

In further studies, the number of people participating in the study can be increased in order to examine the difficulties experienced by people more efficiently. In addition, an experiment can be done to analyze the difficulties and daily routines of people with cerebral palsy while doing the activities in more detail. For this experiment, home environments with different accessibility levels would be suitable. Also, the daily activities stated in the survey can be further detailed, because it was seen in the interview that participants mentioned about many specific activities in addition to the basic daily activities. Furthermore, this study was conducted with Turkish youth, so similar studies can be conducted with young people from other cultures in the future and the results can be compared. Additionally, although young people between the ages of 15-24 were included as participants in this study, as it is characterized as the

transition from dependence to independence, in future studies, individuals aged 15-18 and 18-24 can also be considered and examined separately.



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APPENDICES

APPENDIX A
(THE PETITION OF THE SERÇEV ASSOCIATION)



Sayı : 22-02-118-100

23.03.2022

Konu : Bilkent Üniv. Etik Kurul hk.

İ.D. Bilkent Üniversitesi İnsan Araştırmaları Etik Kurulu'na;

Serçev (Serebral Palsili Çocuklar Derneği) olarak, İ.D. Bilkent Üniversitesi İç Mimarlık ve Çevre Tasarımı bölümü master öğrencisi Pınar Tanrıverdi ile bir iş birliği içerisindeyiz. Çalışmaya katılması uygun olan katılımcılara ulaşabilmek amacıyla, Serçev veri tabanında bulunan kişiler incelenecektir. Çalışmaya katılımı uygun bulunan katılımcılar, "Gençlerin Ev Ortamında Yaptıkları Günlük Aktiviteleri Değerlendirmesi" başlığı altında hazırlanan anket sorularına, whatsapp aracılığı ile gönderilecek olan link ile ulaşabileceklerdir. Pınar Tanrıverdi, bu anket vesilesiyle elde ettiği verileri, katılımcıların gizliliğini koruyarak, araştırmasında kullanacaktır.

Pınar Tanrıverdi'nin yürüteceği bu çalışmaya, Serçev olarak, desteğimiz ve iznimiz vardır.

Bilgilerinize arz ederiz.

Kızılırmak Mahallesi, Muhsin Yazıcıoğlu Caddesi, Engelsiz Oyun Parkı İçi Çukurambar/Ankar

APPENDIX B
(THE APPROVAL OF İ.D BİLKENT UNIVERSITY ETHICS
COMMITTEE)



Bilkent Üniversitesi
Akademik İşler Rektör Yardımcılığı

Tarih : 28 Mart 2022
Gönderilen : Burçak Altay
Gönderen : H. Altay Güvenir
İnsan Araştırmaları Etik Kurulu Başkanı
Konu : "Evaluation of ..." çalışması etik kurul onayı

Üniversitemiz İnsan Araştırmaları Etik Kurulu, 28 Mart 2022 tarihli görüşme sonucu, "Evaluation of daily activities of people with disabilities in their home environment" isimli çalışmanız kapsamında yapmayı önerdiğiniz etkinlik için etik onay vermiş bulunmaktadır. Onay, ekte verilmiş olan çalışma önerisi, çalışma yürütücüleri ve bilgilendirme formu için geçerlidir.

Bu onay, yapmayı önerdiğiniz çalışmanın genel bilim etiği açısından bir değerlendirmedir. Çalışmanızda, kurumumuzun değerlendirmesi dışında kalabilen özel etik ve yasal sınırlamalara uymakla ayrıca yükümlüsünüz.

Kovid-19 salgını nedeniyle konulmuş olan kısıtlamaların yürürlükte olduğu süre içinde, tüm komite toplantıları elektronik ortamda yapılmaktadır; aşağıda isimleri bulunan Bilkent Üniversitesi Etik Kurulu Üyeleri adına bu yazıyı imzalama yetkisi kurul başkanındadır.

Etik Kurul Üyeleri:

Ünvan / İsim	Bölüm / Uzmanlık	
Prof.Dr. H. Altay Güvenir	Bilgisayar Mühendisliği	Başkan
Prof.Dr. Erdal Onar	Hukuk	Üye
Prof.Dr. Haldun Özaktaş	Elektrik ve Elektronik Müh.	Üye
Doç.Dr. Işık Yuluğ	Moleküler Biyoloji ve Genetik	Üye
Dr. Öğr. Üyesi Burcu Aysen Ürgen	Psikoloji	Üye
Dr. Öğr. Üyesi Didem Özkul McGeoch	İletişim ve Tasarım	Yedek Üye
Dr. Öğr. Üyesi A.Barış Özbilen	Hukuk	Yedek Üye

Kurul karar/toplantı No: 2022_03_28_03

APPENDIX C
**(THE SURVEY CONSENT FORM FOR PARTICIPANTS AGED 14-
17 AND THEIR FATHERS)**

Gençlerin Ev Ortamında Yaptıkları Günlük Aktiviteleri Değerlendirmesi

Anket için Bilgi ve Onay Formu (14-17 yaş arası katılımcılar ve ebeveyn-baba için)

Bu anket çalışması, I.D. Bilkent Üniversitesi, İç Mimarlık ve Çevre Tasarımı Bölümü'nde yürütülen bir yüksek lisans tezi kapsamında yapılmaktadır.

Çalışmanın amacı, 14-24 yaş arası serebral palsili gençlerin ev ortamlarında yaptıkları günlük aktivitelerin değerlendirilmesi ve o aktiviteleri yaparken yaşadıkları zorlukları anlamaktır. Anket sonuçlarının incelenip değerlendirilmesi sonrası, günlük aktiviteleri yaparken zorluk yaşanan konuların anlaşılup iyileştirilmesi için önerilerde bulunulması ve bu sayede kişilere daha rahat bir yaşam alanı önermek ve literatüre katkı sağlamak amaçlanmaktadır.

Sizler ile irtibatı, Serçev ile sağladığımız iş birliği sayesinde kurduk.

Anket içerisinde, günlük aktivitelerinizi değerlendirmeniz için yardımcı olacak çoktan seçmeli ve açık uçlu sorular bulunmaktadır. Günlük aktivitelerinizi yaparken yaşadığınız zorluklar, hissettikleriniz ve aktivitelere verdiğiniz önemleri anlamak için sorulan farklı sorular ile karşılaşacaksınız. Bu soruları, gerçek düşünceleriniz ve hisleriniz ile yanıtlamanız beklenmektedir. Anket içerisinde 30 soru bulunmaktadır.

Anket kapsamında toplanan tüm bilgiler gizli tutulacak ve katılımcıların cevapları yalnızca araştırmacıların ulaşabileceği bir yerde saklanacaktır. Elde edilen veriler, bir sonuca varılmak üzere değerlendirilecek ve yalnızca araştırmacı tarafından yayımlanmak üzere raporlanacaktır.

Ankete katılmanızdan kaynaklanan herhangi bir risk veya rahatsızlık öngörülmemektedir. Bu araştırma Bilkent Üniversitesi Bilimsel Araştırma ve Etik kurulu tarafından incelenmiş ve onaylanmıştır. Araştırmacıyı önceden bilgilendirme koşuluyla, katılımcılar istedikleri zaman araştırmadan çekilmekte özgürdür. Ayrıca, katılımcılar istedikleri takdirde, soruları cevaplarırken ebeveynleri yanlarında eşlik edebilirler. Ek olarak, araştırmacı gerekli gördüğü şartlarda katılımcıları çalışmadan uzaklaştırabilir.

Araştırmaya katılarak yaptığınız katkıdan dolayı teşekkür ederiz.

Yukarıdaki bilgiler ışığında araştırmaya gönüllü olarak katılmayı kabul ediyorsanız aşağıdaki kutucuğu işaretleyin. *

1. Katılımcı Onayı*

Yukarıda bahsi geçen araştırmaya gönüllü olarak katılmayı kabul ediyorum.

☐

2. Ebeveyn Onayı* (Sadece 18 yaş altı katılımcılar için gereklidir.)

Baba

Oğlum/kızımın yukarıda bahsi geçen araştırmaya gönüllü olarak katılmasını kabul ediyorum.

☐

Lütfen aşağıdaki soruları okuyun ve sizin için en uygun seçeneği işaretleyin.

APPENDIX D
**(THE SURVEY CONSENT FORM FOR PARTICIPANTS AGED 14-
17 AND THEIR MOTHERS)**

Gençlerin Ev Ortamında Yaptıkları Günlük Aktiviteleri Değerlendirmesi

Anket için Bilgi ve Onay Formu - (14-17 yaş arası katılımcılar ve ebeveyn-anne için)

Bu anket çalışması, I.D. Bilkent Üniversitesi, İç Mimarlık ve Çevre Tasarımı Bölümü'nde yürütülen bir yüksek lisans tezi kapsamında yapılmaktadır.

Çalışmanın amacı, 14-24 yaş arası serebral palsili gençlerin ev ortamlarında yaptıkları günlük aktivitelerin değerlendirilmesi ve o aktiviteleri yaparken yaşadıkları zorlukları anlamaktır. Anket sonuçlarının incelenip değerlendirilmesi sonrası, günlük aktiviteleri yaparken zorluk yaşanan konuların anlaşılıp iyileştirilmesi için önerilerde bulunulması ve bu sayede kişilere daha rahat bir yaşam alanı önermek ve literatüre katkı sağlamak amaçlanmaktadır.

Sizler ile irtibata geçebilmek amacı ile Serçev ile bir iş birliği kurulmuştur.

Anket içerisinde, günlük aktivitelerinizi değerlendirmeniz için yardımcı olacak çoktan seçmeli ve açık uçlu sorular bulunmaktadır. Günlük aktivitelerinizi yaparken yaşadığınız zorluklar, hissettikleriniz ve aktivitelere verdiğiniz önemleri anlamak için sorulan farklı sorular ile karşılaşacaksınız. Bu soruları, gerçek düşünceleriniz ve hisleriniz ile yanıtlamanız beklenmektedir. Anket içerisinde 30 soru bulunmaktadır.

Anket kapsamında toplanan tüm bilgiler gizli tutulacak ve katılımcıların cevapları yalnızca araştırmacıların ulaşabileceği bir yerde saklanacaktır. Elde edilen veriler, bir sonuca varılmak üzere değerlendirilecek ve yalnızca araştırmacı tarafından yayınlanmak üzere raporlanacaktır.

Ankete katılmanızdan kaynaklanan herhangi bir risk veya rahatsızlık öngörülmemektedir. Bu araştırma Bilkent Üniversitesi Bilimsel Araştırma ve Etik kurulu tarafından incelenmiş ve onaylanmıştır. Araştırmacıyı önceden bilgilendirme koşuluyla, katılımcılar istedikleri zaman araştırmadan çekilmekte özgürdür. Ayrıca, katılımcılar istedikleri takdirde, soruları cevaplarken ebeveynleri yanlarında eşlik edebilirler. Ek olarak, araştırmacı gerekli gördüğü şartlarda katılımcıları çalışmadan uzaklaştırabilir.

Araştırmaya katılarak yaptığınız katkıdan dolayı teşekkür ederiz.

Yukarıdaki bilgiler ışığında araştırmaya gönüllü olarak katılmayı kabul ediyorsanız aşağıdaki kutucuğu işaretleyin. *

1. Katılımcı Onayı*

Yukarıda bahsi geçen araştırmaya gönüllü olarak katılmayı kabul ediyorum.

☐

2. Ebeveyn Onayı* (Sadece 18 yaş altı katılımcılar için gereklidir.)

Anne

Oğlum/kızımın yukarıda bahsi geçen araştırmaya gönüllü olarak katılmasını kabul ediyorum.

☐

Lütfen aşağıdaki soruları okuyun ve sizin için en uygun seçeneği işaretleyin.

APPENDIX E
(THE SURVEY CONSENT FORM FOR PARTICIPANTS AGED
ABOVE 18)

Gençlerin Ev Ortamında Yaptıkları Günlük Aktiviteleri Değerlendirmesi

Anket için Bilgi ve Onay Formu - (18 yaş üstü katılımcılar için)

Bu anket çalışması, I.D. Bilkent Üniversitesi, İç Mimarlık ve Çevre Tasarımı Bölümü'nde yürütülen bir yüksek lisans tezi kapsamında yapılmaktadır.

Çalışmanın amacı, 14-24 yaş arası serebral palsili gençlerin ev ortamlarında yaptıkları günlük aktivitelerin değerlendirilmesi ve o aktiviteleri yaparken yaşadıkları zorlukları anlamaktır. Anket sonuçlarının incelenip değerlendirilmesi sonrası, günlük aktiviteleri yaparken zorluk yaşanan konuların anlaşılıp iyileştirilmesi için önerilerde bulunulması ve bu sayede kişilere daha rahat bir yaşam alanı önermek ve literatüre katkı sağlamak amaçlanmaktadır.

Sizler ile irtibatı, Serçev ile yaptığımız iş birliği sayesinde kurduk.

Anket içerisinde, günlük aktivitelerinizi değerlendirmeniz için yardımcı olacak çoktan seçmeli ve açık uçlu sorular bulunmaktadır. Günlük aktivitelerinizi yaparken yaşadığınız zorluklar, hissettikleriniz ve aktivitelere verdiğiniz önemleri anlamak için sorulan farklı sorular ile karşılaşacaksınız. Bu soruları, gerçek düşünceleriniz ve hisleriniz ile yanıtlamanız beklenmektedir. Anket içerisinde 30 soru bulunmaktadır.

Anket kapsamında toplanan tüm bilgiler gizli tutulacak ve katılımcıların cevapları yalnızca araştırmacıların ulaşabileceği bir yerde saklanacaktır. Elde edilen veriler, bir sonuca varılmak üzere değerlendirilecek ve yalnızca araştırmacı tarafından yayınlanmak üzere raporlanacaktır.

Ankete katılımınızdan kaynaklanan herhangi bir risk veya rahatsızlık öngörülmemektedir. Bu araştırma Bilkent Üniversitesi Bilimsel Araştırma ve Etik kurulu tarafından incelenmiş ve onaylanmıştır. Araştırmacıyı önceden bilgilendirme koşuluyla, katılımcılar istedikleri zaman araştırmadan çekilmekte özgürdür. Ayrıca araştırmacı gerekli gördüğü şartlarda katılımcıları çalışmadan uzaklaştırabilir.

Araştırmaya katılarak yaptığınız katkıdan dolayı teşekkür ederiz.

Yukarıdaki bilgiler ışığında araştırmaya gönüllü olarak katılmayı kabul ediyorsanız aşağıdaki kutucuğu işaretleyin. *

1. Katılımcı Onayı*

Yukarıda bahsi geçen araştırmaya gönüllü olarak katılmayı kabul ediyorum.

☐

Lütfen aşağıdaki soruları okuyun ve sizin için en uygun seçeneği işaretleyin.

APPENDIX F
(TURKISH VERSION OF THE SURVEY)

Bölüm 1: Demografik Sorular

1. Cinsiyetiniz nedir?

- ☐ Kadın ☐ Erkek ☐ Cevap vermek istemiyorum

2. Kaç yaşındasınız?

3. Çalışma durumunuz nedir?

- ☐ Çalışıyorum ☐ Öğrenci ☐ Çalışmıyorum

☐ Diğer (lütfen belirtin)

4. Ne tür bir evde kalıyorsunuz?

- ☐ Apartman dairesi ☐ Müstakil ev

☐ Diğer (lütfen belirtin)

5. Eviniz kaç metrekaredir? (Eğer bilmiyorsanız kaç odalı olduğunu yazınız)

6. Yalnız mı yaşıyorsunuz?

- ☐ Evet ☐ Hayır

Biriyle yaşıyorsanız kiminle/kimlerle yaşıyorsunuz?

7. Aşağıdaki yardımcı elemanlardan birini kullanıyor musunuz?

- ☐ Manuel tekerlekli sandalye ☐ Elektrikli tekerlekli sandalye ☐ Koltuk değneği
☐ Kullanmıyorum

Yukarıdaki elemanlardan birini kullanıyorsanız, ne kadar zamandır kullanıyorsunuz?

Bölüm 2: Fiziksel Farkındalık Soruları

8. Aşağıdaki sorulara katılma seviyenizi belirtiniz.

	Kesinlikle katılmıyorum	Katılmıyorum	Kararsızım	Katılıyorum	Kesinlikle katılıyorum
Kollarımı kullanırken zorluk yaşıyorum.	☐	☐	☐	☐	☐
Ellerimi kullanırken zorluk yaşıyorum.	☐	☐	☐	☐	☐
Bacaklarımı kullanırken zorluk yaşıyorum.	☐	☐	☐	☐	☐
Eşyaları tutarken/kullanırken zorluk yaşıyorum.	☐	☐	☐	☐	☐
Tekerlekli sandalyemi/koltuk değneğimi kullanırken zorluk yaşıyorum (Kullanmıyorsanız soruyu atlayınız).	☐	☐	☐	☐	☐
Herhangi bir yardım almadan hareket ederken zorluk yaşıyorum.	☐	☐	☐	☐	☐

Bölüm 3: Zorluk Soruları

Günlük aktiviteleri yaparken...

9. Yardım almadan yemek hazırlayabiliyor musunuz?

(Örneğin elma doğramak veya salata hazırlamak)

☐ Evet ☐ Hayır

Hazırlayamıyorsanız nedenini açıklayınız?

10. Yardım almadan giyinebiliyor musunuz?

(Örneğin kıyafetlerinizi askıdan alıp giyinmek)

☐ Evet ☐ Hayır

Giyinmiyorsanız nedenini açıklayınız?

11. Yardım almadan giysilerinizi yıkayabiliyor musunuz?

(Örneğin giysileri çamaşır makinesine atmak ve çamaşırları asmak)

☐ Evet ☐ Hayır

Yıkayamıyorsanız nedenini açıklayınız?

12. Yardım almadan tuvaleti kullanabiliyor musunuz?

(Örneğin klozete oturup kalkmak)

☐ Evet ☐ Hayır

Kullanamıyorsanız nedenini açıklayınız?

13. Yardım almadan banyo yapabiliyor musunuz?

(Örneğin duş/küvetin içine girip yıkanabilmek)

☐ Evet ☐ Hayır

Yapamıyorsanız nedenini açıklayınız?

14. Lütfen aşağıdaki sorulara katılma seviyenizi belirtiniz.

	Kesinlikle katılmıyorum	Katılmıyorum	Kararsızım	Katılıyorum	Kesinlikle katılıyorum
Yemek hazırlarken (Örneğin elma doğramak veya salata hazırlamak) zorluk yaşıyorum.	☐	☐	☐	☐	☐
Giyinirken (Örneğin kıyafetlerinizi askıdan alıp giymek) zorluk yaşıyorum.	☐	☐	☐	☐	☐
Giyislerimi yıkarken (Örneğin giysileri çamaşır makinesine atmak ve çamaşırını asmak) zorluk yaşıyorum.	☐	☐	☐	☐	☐
Tuvaleti kullanırken (Örneğin klozete oturup kalkmak) zorluk yaşıyorum	☐	☐	☐	☐	☐
Banyo yaparken (Örneğin duş/küvetin içine girip yıkatabilmek) zorluk yaşıyorum	☐	☐	☐	☐	☐

15. Evinizde yaparken en çok zorlandığınız aktivite/aktiviteler hangisidir? (Birden fazla aktivite işaretleyebilirsiniz)

☐ Yemek hazırlamak ☐ Giyinmek ☐ Giysileri yıkamak ☐ Tuvaleti kullanmak

☐ Banyo yapmak

☐ Diğer (lütfen belirtin)

16. Evinizdeki genel hareket kabiliyetinizi nasıl değerlendirirsiniz?

☐ Hiç memnun değilim ☐ Memnun değilim ☐ Kararsızım ☐ Memnunum

☐ Çok memnunum

Memnun değilseniz neden?

17. Giyinirken yaşadığınız zorluklar nelerdir?
(Örneğin kıyafetlerinizi askıdan alıp giyinmek)

18. Sizin için yatak odanızda yaşadığınız en büyük zorluklar nelerdir?
(Oda içerisinde rahat hareket edebilme, eşyalara erişebilme... vb)

19. Yemek hazırlarken yaşadığınız zorluklar nelerdir?
(Örneğin elma doğramak veya salata hazırlamak)

20. Sizin için mutfakta yaşadığınız en büyük zorluklar nelerdir?
(Oda içerisinde rahat hareket edebilme, eşyalara erişebilme... vb)

21. Giysilerinizi yıkarken yaşadığınız zorluklar nelerdir?
(Örneğin giysileri çamaşır makinesine atmak ve çamaşırları asmak)

22. Sizin için banyoda yaşadığınız en büyük zorluklar nelerdir?
(Oda içerisinde rahat hareket edebilme, eşyalara erişebilme... vb)

23. Evinizin içerisinde genel olarak yaparken zorlandığınız diğer aktiviteler nelerdir? Neden?

Bölüm 4: Bağımsızlık Soruları

24. Lütfen aşağıdaki sorulara katılma seviyenizi belirtiniz.

	Kesinlikle katılmıyorum	Katılmıyorum	Kararsızım	Katılıyorum	Kesinlikle katılıyorum
Hareket ederken yaşadığım zorluklar yaşam kalitemi etkiliyor.	☐	☐	☐	☐	☐
Yaşadığım zorluklar tek başımayken çözülemeyecek sorunlardır.	☐	☐	☐	☐	☐
Günlük aktivitelerimi yaparken yaşadığım hareketlilik zorlukları beni birine bağımlı hissettiriyor.	☐	☐	☐	☐	☐
Yemek hazırlarken birine bağımlı hissediyorum (Yardıma ihtiyaç duyma konusunda).	☐	☐	☐	☐	☐
Giyinirken birine bağımlı hissediyorum (Yardıma ihtiyaç duyma konusunda).	☐	☐	☐	☐	☐
Giysileri yıkarken birine bağımlı hissediyorum (Yardıma ihtiyaç duyma konusunda).	☐	☐	☐	☐	☐
Tuvaleti kullanırken birine bağımlı hissediyorum (Yardıma ihtiyaç duyma konusunda).	☐	☐	☐	☐	☐
Banyo yaparken birine bağımlı hissediyorum (Yardıma ihtiyaç duyma konusunda).	☐	☐	☐	☐	☐
Günlük aktiviteleri yaparken birinin yardım etmesi beni rahat hissettiriyor.	☐	☐	☐	☐	☐
Günlük aktiviteleri yaparken birinin yardım etmesi beni mutsuz hissettiriyor.	☐	☐	☐	☐	☐
Günlük aktiviteleri yaparken birinin yardım etmesi beni	☐	☐	☐	☐	☐

suçlu hissettiriyor.

Günlük aktiviteleri yaparken birilerinden yardım almak size nasıl hissettiriyor? Kısaca açıkla mısınız?

25. Hangi aktiviteyi/aktiviteleri yaparken daha çok birine bağımlı hissediyorsun? (Birden fazla aktivite işaretleyebilirsiniz)

☐ Yemek
hazırlamak

☐ Giyinmek

☐ Giysileri
yıkamak

☐ Tuvalete
gitmek

☐ Banyo yapmak

☐ Diğer (lütfen belirtin)

26. Evinizde hareket kabiliyetinizi artıran özel bir düzenleme var mı? Varsa size nasıl kolaylık sağlıyor?

27. Eğer evinizde özel bir düzenleme yoksa, kendinizi daha bağımsız hissetmek için evinizde neyi değiştirmek veya düzeltmek istersiniz?

Bölüm 5: Önemlilik Soruları

28. Lütfen aşağıdaki sorularda aktivitelerin sizin için ne kadar önemli olduğunu belirtiniz.

	Kesinlikle katılmıyorum	Katılmıyorum	Kararsızım	Katılıyorum	Kesinlikle katılıyorum
Kendi başıma yemek hazırlayabilmek benim için önemlidir	☐	☐	☐	☐	☐
Kendi başıma giyinebilmek benim için önemlidir	☐	☐	☐	☐	☐
Kendi başıma giysilerimi yıkayabilmek benim için önemlidir	☐	☐	☐	☐	☐
Kendi başıma tuvaleti kullanabilmek benim için önemlidir	☐	☐	☐	☐	☐
Kendi başıma banyo yapabilmek benim için önemlidir	☐	☐	☐	☐	☐

29. Kendi başınıza yapabilmemiz için en önemli aktivite/aktiviteler hangisidir? (Birden fazla aktivite işaretleyebilirsiniz)

☐ Yemek hazırlamak ☐ Giyinmek ☐ Giysileri yıkamak ☐ Tuvaleti kullanmak

☐ Banyo yapmak

☐ Diğer (lütfen belirtin)

30. Yardım almadan yapmak istediğiniz en önemli aktiviteyi/aktiviteleri daha detaylı açıklayabilir misiniz?

ÇALIŞMANIN İKİNCİ AŞAMASINA DAVET

Bu çalışmanın veri toplama süreci iki aşamadan oluşmaktadır. İlk aşama, katılım gerçekleştirdiğiniz anket çalışmasıdır. İkinci aşamada, ayarlanacak olan telefon görüşmeleri üzerinden daha detaylı röportajlar gerçekleştirilecektir. Bu görüşme sırasında çok rahat olmanız beklenmektedir. Buradaki amacımız, tamamlamış olduğunuz anketin ötesinde, yaşadığınız zorlukları, isteklerinizi ve duygularınızı daha iyi anlamaktır. Bu yapılandırılmamış bir görüşme olacak ve görüşmemiz anlattıklarınıza göre şekillenecek. Röportaj sırasında en büyük önceliğimiz kendinizi rahat hissetmeniz olduğundan, istediğiniz zaman görüşmeyi sonlandırabiliriz. Öngörülen süre 20 dakikadır. Röportajlar kayıt edilecek ve ulaşımı sadece araştırmacıya açık olacaktır. Verilerin analizi için kayıtlar deşifre edilecek ve yazıya dökülecektir. Röportaja katılmayı kabul etmeniz dahilinde, daha detaylı bilgi edinmeniz ve röportaja katılmayı onaylamanız için size bir onay formu gönderilecektir. Burada, görüşmenin kayıt altına alınmasını kabul edip etmediğinizi soran bir onay daha bulunmaktadır. Dilediğiniz zaman çalışmadan çekilme, röportaj kayıtlarını sildirme ve cevaplarınızda değişiklik yapmak hakkına sahiptir.

Çalışmanın ikinci bölümüne katılım da gönüllülük esasına bağlıdır. Bu formu doldurduktan sonra ikinci aşamaya katılmak istiyorsanız, sizinle e-posta yoluyla iletişime geçebilmemiz için lütfen isminizi ve mail adresinizi aşağıya yazınız.

Adınız/ Soyadınız: _____

e-mail adresiniz: _____

APPENDIX G
(ENGLISH VERSION OF THE SURVEY)

Section 1: Demographic Questions

1. What is your gender?

- ☐ Female ☐ Male ☐ Prefer not to say

2. How old are you?

3. What is your main work status?

- ☐ Working ☐ Student ☐ Not working
☐ Other (Please specify)

4. What type of house do you stay in?

- ☐ Apartment flat ☐ Detached house
☐ Other (Please specify)

5. How many square meters is your house? (If you don't know, write how many rooms it has)

6. Do you live alone?

- ☐ Yes ☐ No

If you live with someone, who do you live with?

7. Are you using any of the following tools? If so, which one are you using?

- ☐ Manual wheelchair ☐ Powered wheelchair ☐ Crutches ☐ Not using

If you are using, how long are you using this tool?

Section 2: Physical Awareness Questions

8. Please indicate your level of agreement with the following questions.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I have difficulty using my arms.	☐	☐	☐	☐	☐
I have difficulty using my hands.	☐	☐	☐	☐	☐
I have difficulty using my legs.	☐	☐	☐	☐	☐
I have difficulty holding/using objects.	☐	☐	☐	☐	☐
I have difficulty using my wheelchair/crutches. (Skip the question if you don't use it)	☐	☐	☐	☐	☐
I have difficulty moving around without any assistance.	☐	☐	☐	☐	☐

Section 3: Difficulty Questions

While doing the daily activities...

9. Can you prepare meals without assistance?

(For example, chopping apples or preparing a salad)

☐ Yes ☐ No

If you can't prepare, can you explain why?

10. Can you dress without assistance?

(For example, taking your clothes off the hanger and getting dressed)

☐ Yes ☐ No

If you can't get dressed, can you explain why?

11. Can you do laundry without assistance?

(For example, throwing clothes in the washing machine and hanging the laundry)

☐ Yes ☐ No

If you can't do, can you explain why?

12. Can you use the toilet without assistance?

(For example, sitting on the toilet)

☐ Yes ☐ No

If you can't use, can you explain why?

13. Can you take a bath without assistance?

(For example, being able to get into the shower/tub)

☐ Yes ☐ No

If you can't take, can you explain why?

14. Please indicate your level of agreement with the following questions.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I have difficulty while preparing meal (For example, chopping apples or preparing salad).	☐	☐	☐	☐	☐
I have difficulty getting dressed (For example, taking your clothes off the hanger and getting dressed).	☐	☐	☐	☐	☐
I have difficulty doing laundry (For example, throwing clothes in the washing machine and hanging the laundry).	☐	☐	☐	☐	☐
I have difficulty using the toilet (For example, sitting on the toilet).	☐	☐	☐	☐	☐
I have difficulty taking a bath (For example, being able to get into the shower/tub).	☐	☐	☐	☐	☐

15. What activity/activities do you find the most difficult to do at home? (You can mark more than one activity)

- ☐ Preparing meals
 ☐ Getting dressed
 ☐ Doing laundry
 ☐ Using the toilet
- ☐ Having a shower
- ☐ Other (Please specify)

16. How would you rate your general mobility in your home?

- ☐ Very unsatisfied
 ☐ Unsatisfied
 ☐ Undecided
 ☐ Satisfied
 ☐ Very satisfied

If you are unsatisfied, can you explain why?

17. What difficulties do you have while dressing?

(For example, taking your clothes off the hanger and getting dressed)

18. What are the biggest challenges for you in your bedroom?

(Moving freely in the room, accessing things, etc.)

19. What difficulties do you have while preparing meals?

(For example, chopping apples or preparing a salad)

20. What are the biggest challenges for you in the kitchen?

(Moving freely in the room, accessing things, etc.)

21. What difficulties do you experience while doing laundry?

(For example, throwing clothes in the washing machine and hanging the laundry)

22. What are the biggest challenges for you in the bathroom?

(Moving freely in the room, accessing things, etc.)

23. What are the other activities that you find difficult to do in your home in general? Why?

Section 4: Independency Questions

24. Please indicate your level of agreement with the following questions.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The difficulties I experience while moving around affect my quality of life.	☐	☐	☐	☐	☐
The difficulties I face are problems that cannot be solved on my own.	☐	☐	☐	☐	☐
The mobility difficulties I experience while doing my daily activities make me feel dependent on someone.	☐	☐	☐	☐	☐
I feel dependent on someone while preparing meal.	☐	☐	☐	☐	☐
I feel dependent on someone while dressing.	☐	☐	☐	☐	☐
I feel dependent on someone while doing laundry.	☐	☐	☐	☐	☐
I feel dependent on someone while using the toilet.	☐	☐	☐	☐	☐
I feel dependent on someone while taking a bath.	☐	☐	☐	☐	☐
It makes me feel comfortable to have someone help with daily activities.	☐	☐	☐	☐	☐
It makes me feel unhappy to have someone help with daily activities.	☐	☐	☐	☐	☐
It makes me feel guilty to have someone help with daily activities.	☐	☐	☐	☐	☐

How does it feel to get help from someone while doing daily activities? Can you explain briefly?

25. Which activity/activities do you feel most dependent on? (You can mark more than one activity)

☐ Preparing meals

☐ Getting dressed

☐ Doing laundry

☐ Using the toilet

☐ Having a shower

☐ Other (Please specify)

26. Is there any special arrangement in your home that increases your mobility? If yes, how does it help you?

27. If there is no special arrangement in your home, what would you like to change or fix in your home to make you feel more independent?

Section 5: Importance Questions

28. Please indicate how important the activities are to you in the questions below.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Being able to prepare meals by myself is important to me	☐	☐	☐	☐	☐
Being able to get dressed by myself is important to me	☐	☐	☐	☐	☐
Being able to do laundry by myself is important to me	☐	☐	☐	☐	☐
Being able to use the toilet by myself is important to me	☐	☐	☐	☐	☐
Being able to take a bath by myself is important to me	☐	☐	☐	☐	☐

29. What is the most important activity/activities for you to do on your own? (You can mark more than one activity)

- ☐ Preparing meals
 ☐ Getting dressed
 ☐ Doing laundry
 ☐ Using the toilet
- ☐ Having a shower
- ☐ Other (Please specify)

30. Can you describe in more detail the most important activity/activities you want to do without help?

INVITATION TO THE SECOND STAGE OF THE STUDY

The data collection process of this study consists of two stages. The first stage is the survey that you participated in. In the second stage, detailed interviews will be conducted over the phone calls to be arranged. You are expected to be very comfortable during this interview. Our aim here is to better understand the difficulties, wishes and feelings while doing daily activities. This will be an unstructured interview and our conversation will be shaped by what you say. Since our top priority during the interview is that you feel comfortable, we can end the interview at any time. Estimated time is 20 minutes. Interviews will be recorded and accessible only to the researcher. For the analysis of the data, the records will be deciphered and transcribed. Once you have agreed to participate in the interview, a consent form will be sent to you to obtain more detailed information and to confirm your participation in the interview. Also, you will see another confirmation in the consent form that asks if you agree to have the conversation recorded. You have the right to withdraw from the study, to delete the interview recordings and to make changes in your answers at any time.

Participation in the second part of the study is also voluntary. If you want to participate in the second stage, please write your name and e-mail address below so that we can contact you via e-mail.

Name/ Surname: _____

e-mail adress: _____

APPENDIX H
(THE INTERVIEW CONSENT FORM FOR PARTICIPANTS AGED
14-17 AND THEIR FATHERS)

Gençlerin Ev Ortamında Yaptıkları Günlük Aktiviteleri Değerlendirmesi

Röportaj için Bilgi ve Onay Formu – (14-17 yaş arası katılımcılar ve ebeveyn-baba için)

Bu röportaj çalışması, I.D. Bilkent Üniversitesi, İç Mimarlık ve Çevre Tasarımı Bölümü'nde yürütülen bir yüksek lisans tezi kapsamında yapılmaktadır.

Çalışmanın amacı, 14-24 yaş arası serebral palsili gençlerin ev ortamlarında yaptıkları günlük aktivitelerin değerlendirilmesi ve o aktiviteleri yaparken yaşadıkları zorlukları anlamaktır. Çalışma sonuçlarının incelenip değerlendirilmesi sonrası, günlük aktiviteleri yaparken zorluk yaşanan konuların anlaşılıp iyileştirilmesi için önerilerde bulunulması ve bu sayede kişilere daha rahat bir yaşam alanı önermek ve literatüre katkı sağlamak amaçlanmaktadır.

Sizler ile irtibata geçebilmek amacı ile Serçev ile bir iş birliği kurulmuştur.

Çalışmanın bu aşamasında sizinle telefon görüşmesi aracılığı ile bir röportaj yapılacaktır. Bu görüşme sırasında çok rahat olmanız bekleniyor. Buradaki amacımız, tamamlanmış olduğunuz anketin ötesinde, yaşadığınız zorlukları, isteklerinizi ve duygularınızı daha iyi anlamaktır. Bu yapılandırılmamış bir görüşme olacak ve görüşmemiz anlattıklarınıza göre şekillenecek. Mülakat sırasında en büyük önceliğimiz kendinizi rahat hissetmeniz olduğundan, her an sonlandırabiliriz. Öngörülen süre 20 dakikadır.

Onay verdiğiniz takdirde, gerçekleştirdiğimiz görüşme kaydedilecektir. Lütfen aşağıda, röportajın kaydedilmesine onay verip vermediğinizi belirtiniz.

Röportaj kapsamında toplanan tüm bilgiler gizli tutulacak ve katılımcıların cevapları yalnızca araştırmacıların ulaşabileceği bir yerde saklanacaktır. Elde edilen veriler, bir sonuca varılmak üzere değerlendirilecek ve yalnızca araştırmacı tarafından yayımlanmak üzere raporlanacaktır.

Röportaja katılmanızdan kaynaklanan herhangi bir risk veya rahatsızlık öngörülmektedir. Bu araştırma Bilkent Üniversitesi Bilimsel Araştırma ve Etik kurulu tarafından incelenmiş ve onaylanmıştır. Araştırmacıyı önceden bilgilendirme koşuluyla, katılımcılar istedikleri zaman araştırmadan çekilmekte özgürdür. Ayrıca, katılımcılar istedikleri takdirde, soruları cevaplarken ebeveynleri yanlarında eşlik edebilirler. Ek olarak, araştırmacı gerekli gördüğü şartlarda katılımcıları çalışmadan uzaklaştırabilir.

Araştırmaya katılarak yaptığınız katkıdan dolayı teşekkür ederiz.

Yukandaki bilgiler ışığında araştırmaya gönüllü olarak katılmayı kabul ediyorsanız aşağıdaki kutucuğu işaretleyin. *

1. Katılımcı Onayı*

Yukanda bahsi geçen araştırmaya gönüllü olarak katılmayı kabul ediyorum. ☐

Yukanda bahsi geçen röportajın kaydedilmesine onay veriyorum. ☐

Onay vermiyorum. ☐

2. Ebeveyn Onayı* (Sadece 18 yaş altı katılımcılar için gereklidir.)

Baba

Oğlum/kızımın yukanda bahsi geçen araştırmaya gönüllü olarak katılmasını kabul ediyorum. ☐

Yukanda bahsi geçen röportajın kaydedilmesine onay veriyorum. ☐

Onay vermiyorum. ☐

APPENDIX I
(THE INTERVIEW CONSENT FORM FOR PARTICIPANTS AGED
14-17 AND THEIR MOTHERS)

Gençlerin Ev Ortamında Yaptıkları Günlük Aktiviteleri Değerlendirmesi

Röportaj için Bilgi ve Onay Formu- (14-17 yaş arası katılımcılar ve ebeveyn-anne için)

Bu röportaj çalışması, I.D. Bilkent Üniversitesi, İç Mimarlık ve Çevre Tasarımı Bölümü'nde yürütülen bir yüksek lisans tezi kapsamında yapılmaktadır.

Çalışmanın amacı, 14-24 yaş arası serebral palsili gençlerin ev ortamlarında yaptıkları günlük aktivitelerin değerlendirilmesi ve o aktiviteleri yaparken yaşadıkları zorlukları anlamaktır. Çalışma sonuçlarının incelenip değerlendirilmesi sonrası, günlük aktiviteleri yaparken zorluk yaşanan konuların anlaşılıp iyileştirilmesi için önerilerde bulunulması ve bu sayede kişilere daha rahat bir yaşam alanı önermek ve literatüre katkı sağlamak amaçlanmaktadır.

Sizler ile irtibata geçebilmek amacı ile Serçev ile bir iş birliği kurulmuştur.

Çalışmanın bu aşamasında sizinle telefon görüşmesi aracılığı ile bir röportaj yapılacaktır. Bu görüşme sırasında çok rahat olmanız bekleniyor. Buradaki amacımız, tamamlamış olduğunuz anketin ötesinde, yaşadığınız zorlukları, isteklerinizi ve duygularınızı daha iyi anlamaktır. Bu yapılandırılmamış bir görüşme olacak ve görüşmemiz anlattıklarınıza göre şekillenecek. Mülakat sırasında en büyük önceliğimiz kendinizi rahat hissetmeniz olduğundan, her an sonlandırabiliriz. Öngörülen süre 20 dakikadır.

Onay verdiğiniz takdirde, gerçekleştirdiğimiz görüşme kaydedilecektir. Lütfen aşağıda, röportajın kaydedilmesine onay verip vermediğinizi belirtiniz.

Röportaj kapsamında toplanan tüm bilgiler gizli tutulacak ve katılımcıların cevapları yalnızca araştırmacıların ulaşabileceği bir yerde saklanacaktır. Elde edilen veriler, bir sonuca varılmak üzere değerlendirilecek ve yalnızca araştırmacı tarafından yayımlanmak üzere raporlanacaktır.

Röportaja katılmanızdan kaynaklanan herhangi bir risk veya rahatsızlık öngörülmemektedir. Bu araştırma Bilkent Üniversitesi Bilimsel Araştırma ve Etik kurulu tarafından incelenmiş ve onaylanmıştır. Araştırmacıyı önceden bilgilendirme koşuluyla, katılımcılar istedikleri zaman araştırmadan çekilmekte özgürdür. Ayrıca, katılımcılar istedikleri takdirde, soruları cevaplarken ebeveynleri yanlarında eşlik edebilirler. Ek olarak, araştırmacı gerekli gördüğü şartlarda katılımcıları çalışmadan uzaklaştırabilir.

Araştırmaya katılarak yaptığınız katkıdan dolayı teşekkür ederiz.

Yukarıdaki bilgiler ışığında araştırmaya gönüllü olarak katılmayı kabul ediyorsanız aşağıdaki kutucuğu işaretleyin. *

1. Katılımcı Onayı*

Yukarıda bahsi geçen araştırmaya gönüllü olarak katılmayı kabul ediyorum. ☐

Yukarıda bahsi geçen röportajın kaydedilmesine onay veriyorum. ☐

Onay vermiyorum. ☐

2. Ebeveyn Onayı* (Sadece 18 yaş altı katılımcılar için gereklidir.)

Anne

Oğlum/kızımın yukarıda bahsi geçen araştırmaya gönüllü olarak katılmasını kabul ediyorum. ☐

Yukarıda bahsi geçen röportajın kaydedilmesine onay veriyorum. ☐

Onay vermiyorum. ☐

APPENDIX J
(THE INTERVIEW CONSENT FORM FOR PARTICIPANTS AGED
ABOVE 18)

Gençlerin Ev Ortamında Yaptıkları Günlük Aktiviteleri Değerlendirmesi

Röportaj için Bilgi ve Onay Formu – (18 Yaş üstü katılımcılar için)

Bu röportaj çalışması, İ.D. Bilkent Üniversitesi, İç Mimarlık ve Çevre Tasarımı Bölümü'nde yürütülen bir yüksek lisans tezi kapsamında yapılmaktadır.

Çalışmanın amacı, 14-24 yaş arası serebral palsili gençlerin ev ortamlarında yaptıkları günlük aktivitelerin değerlendirilmesi ve o aktiviteleri yaparken yaşadıkları zorlukları anlamaktır. Çalışma sonuçlarının incelenip değerlendirilmesi sonrası, günlük aktiviteleri yaparken zorluk yaşanan konuların anlaşılıp iyileştirilmesi için önerilerde bulunulması ve bu sayede kişilere daha rahat bir yaşam alanı önermek ve literatüre katkı sağlamak amaçlanmaktadır.

Sizler ile irtibata geçebilmek amacı ile Serçev ile bir iş birliği kurulmuştur.

Çalışmanın bu aşamasında sizinle telefon görüşmesi aracılığı ile bir röportaj yapılacaktır. Bu görüşme sırasında çok rahat olmanız bekleniyor. Buradaki amacımız, tamamlanmış olduğunuz anketin ötesinde, yaşadığınız zorlukları, isteklerinizi ve duygularınızı daha iyi anlamaktır. Bu yapılandırılmamış bir görüşme olacak ve görüşmemiz anlattıklarınıza göre şekillenecek. Mülakat sırasında en büyük önceliğimiz kendinizi rahat hissetmeniz olduğundan, her an sonlandırabiliriz. Öngörülen süre 20 dakikadır.

Onay verdiğiniz takdirde, gerçekleştirdiğimiz görüşme kaydedilecektir. Lütfen aşağıda, röportajın kaydedilmesine onay verip vermediğinizi belirtiniz.

Röportaj kapsamında toplanan tüm bilgiler gizli tutulacak ve katılımcıların cevapları yalnızca araştırmacıların ulaşabileceği bir yerde saklanacaktır. Elde edilen veriler, bir sonuca varılmak üzere değerlendirilecek ve yalnızca araştırmacı tarafından yayımlanmak üzere raporlanacaktır.

Röportaja katılmanızdan kaynaklanan herhangi bir risk veya rahatsızlık öngörülmektedir. Bu araştırma Bilkent Üniversitesi Bilimsel Araştırma ve Etik kurulu tarafından incelenmiş ve onaylanmıştır. Araştırmacıyı önceden bilgilendirme koşuluyla, katılımcılar istedikleri zaman araştırmadan çekilmekte özgürdür. Ayrıca, katılımcılar istedikleri takdirde, soruları cevaplatırken ebeveynleri yanlarında eşlik edebilirler. Ek olarak, araştırmacı gerekli gördüğü şartlarda katılımcıları çalışmadan uzaklaştırabilir.

Araştırmaya katılarak yaptığınız katkıdan dolayı teşekkür ederiz.

Yukandaki bilgiler ışığında araştırmaya gönüllü olarak katılmayı kabul ediyorsanız aşağıdaki kutucuğu işaretleyin. *

1. Katılımcı Onayı*

Yukarıda bahsi geçen araştırmaya gönüllü olarak katılmayı kabul ediyorum.

☐

Yukarıda bahsi geçen röportajın kaydedilmesine onay veriyorum.

☐

Onay vermiyorum.

☐

