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SELF-EMPOWERMENT THROUGH MAKING: EXPLORING THE INVOLVEMENT EXPERIENCES OF PEOPLE WITH DISABILITIES IN DESIGNING AND ADAPTING ASSISTIVE PRODUCTS

A THESIS SUBMITTED TO
THE GRADUATE SCHOOL OF NATURAL AND APPLIED SCIENCES
OF
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BY

KORAY CANLAR

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR
THE DEGREE OF MASTER OF SCIENCE
IN
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Approval of the thesis:

SELF-EMPOWERMENT THROUGH MAKING: EXPLORING THE INVOLVEMENT EXPERIENCES OF PEOPLE WITH DISABILITIES IN DESIGNING AND ADAPTING ASSISTIVE PRODUCTS

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ABSTRACT

SELF-EMPOWERMENT THROUGH MAKING: EXPLORING THE INVOLVEMENT EXPERIENCES OF PEOPLE WITH DISABILITIES IN DESIGNING AND ADAPTING ASSISTIVE PRODUCTS

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Master of Science, Industrial Design
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The effects of disabilities can vary significantly between individuals (e.g., function and body structure problems, limitations, or prevention of involvement in activities). This variability in the needs of people with disabilities demands inclusive and universal design approaches and personalized assistive solutions which empower people with disabilities, allowing them to have more control over their actions and to participate in activities. The empowering potential of the maker movement and production activities for individuals with disabilities is apparent, but not thoroughly investigated. In this thesis research, the empowerment of people with physical disabilities through their involvement in designing, making, and adapting processes of their own assistive products are investigated from the developing country context of Turkey. The research utilizes semi-structured interviews and participant observations of people with various physical disabilities. The study highlights most significantly that individually specific disabilities affect both assistive product use and community participation, that there is a need to personalize assistive products, and that people with disabilities tend to form personal networks for making activities.

Keywords: Disability, Inclusive Design, Maker Movement, Empowerment, Assistive Products.

ÖZ

YAPMA YOLUYLA KENDİNİ GÜÇLENDİRME: ENGELLİ BİREYLERİN YARDIMCI ÜRÜNLERİ TASARLAMA VE UYARLAMA SÜREÇLERİNE KATILIM DENEYİMLERİNİN İNCELENMESİ

Canlar, Koray
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Eylül 2022, 171 sayfa

Engelliliğin etkileri bireyler arasında önemli ölçüde farklılık gösterebilir (örneğin, işlev ve vücut yapısı sorunları, faaliyetlere katılımın sınırlandırılması veya engellenmesi). Engelli bireylerin ihtiyaçlarındaki bu değişkenlik, onları güçlendirmeyi, eylemleri üzerinde daha fazla kontrol sahibi olmalarını ve faaliyetlere katılmalarını amaçlayan kapsayıcı ve evrensel tasarım yaklaşımlarını ve kişiselleştirilmiş yardımcı çözümleri gerektirmektedir. Engelli bireyler için maker hareketinin ve üretim faaliyetlerinin güçlendirici potansiyeli açıktır, ancak yeterince araştırılmamıştır. Bu tez çalışmasında, fiziksel engelli bireylerin kendi yardımcı ürünlerini tasarlama, yapma ve uyarlama süreçlerine katılımları yoluyla güçlendirilmeleri, gelişmekte olan Türkiye bağlamında incelenmektedir. Araştırmada, çeşitli fiziksel engelleri olan kişilerle yarı yapılandırılmış görüşmeler ve katılımcı gözlemleri kullanılmıştır. Çalışmanın en önemli bulguları, bireysel engellerin hem yardımcı ürün kullanımını hem de toplumsal katılımı etkilediği, yardımcı ürünlerin kişiselleştirilmesine ihtiyaç duyulduğu ve engelli kişilerin faaliyetlerde bulunmak için kişisel ağlar oluşturma eğiliminde olduklarıdır.

Anahtar Kelimeler: Engellilik, Kapsayıcı Tasarım, Maker Haraketi, Güçlendirme, Yardımcı Ürünler

In remembrance of my loving grandmother

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TABLE OF CONTENTS

CHAPTERS

APPENDICES

LIST OF TABLES

TABLES

LIST OF FIGURES

FIGURES

LIST OF ABBREVIATIONS

ABBREVIATIONS

CP: Cerebral Palsy

DIY: Do-It-Yourself

DIY-AT: Do-It-Yourself Assistive Technologies

EIDD: The European Institute for Design and Disability

HCI: Human-Computer Interaction

HSP: Hereditary Spastic Paraplegias

IT: Information Technologies

NCSU: North Carolina State University

TÜİK: Turkish Statistical Institute

UCD: User-Centred Design

CHAPTER 1

INTRODUCTION

The term disability is relative in the sense that it shows itself differently in every context and for every person, making it an overall term that includes a decrease in functions, problems in body structure, limitations to activities, or prevention of involvement in an environment (Persson et al., 2015). This relativity of the concept of disability led to inclusive designing for disability approaches in literature, such as *universal design* that is defined as ‘‘the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (Connell et al., 1997). A separate design approach that is used in synergy with designing for disability is *participatory design* which aims to develop the idea through iterations generated with interactions between the designers and users (Spinuzzi, 2005).

When looking at the aims of designing for disability, using such universal and participatory design approaches ultimately intend to empower the people with disabilities that they design for. How a person with disability, or any person, can be empowered, and the requirements for the empowerment are highly dependent on the individual and the specific context (Zimmerman, 2000). The variation in what it means to be empowered is increased further in the context of disability by the individual differences in abilities and limitations even within the same disability group project (Gregor et al., 2002).

In all this ambiguity and relativeness of both the terms of empowerment and disability, there is a framework that can be used to investigate and evaluate the empowering effects of a product, an activity, or a context of community on people with disabilities. *The Empowerment Theory* by Zimmerman (2000) provides three elements that can constitute the empowerment of a person:

- being able to control and access resources,
- participating with others, and
- having critical awareness of the socio-political environment.

Looking at these elements, the aims of universal and participatory design align with the empowerment of the users. Another design approach that involves the people's participation is *open design*, which also advocates for the access to design information without limitations in order for people to participate in the process of improving and adapting the ideas (Bakırlıoğlu & Kohtala, 2019). Building from the concept of open design and its participatory nature, the *maker movement and making activities* promotes the access to the means of *learning-by-doing* in collaborative maker spaces where people with similar interests meet (Bosse et al., 2018). By involving in making activities in such collaborative contexts, a person becomes aware of their set of abilities and limitations in relation to their social environment.

Raising from these foundations, this study focuses on the extent of the empowering effects of the maker movement and collective production activities on people with disabilities and the assistive products they use. People with physical disabilities are selected as the target group to improve the chances of participant involvement in making and adapting activities for their assistive products.

1.1 Aims & Objectives of the Study

The objectives of this study are to understand the needs and attitudes of people with physical disabilities towards various communities and/or maker projects, the extent of variance in physical disabilities, the community-related and daily life experiences of highly specific assistive product users, and the motivations for and the extent of user participation in the making, maintaining and improving said assistive tools and devices.

In this way, the main aim of this study is to:

- Explore and determine how active people with physical disabilities are in the production and design processes of their own assistive products.

The goals of the study are:

- Understanding the empowering effect of the resulting products and community co-production activities on the social and daily lives of people with physical disabilities.
- Developing key points, design insights and suggestions for improving these empowering effects.

1.2 Research Questions

The main research question of the study is:

- What is the role of making and collective production activities for enabling the participation of people with disabilities and empowering them in designing, adapting and making their own assistive products?

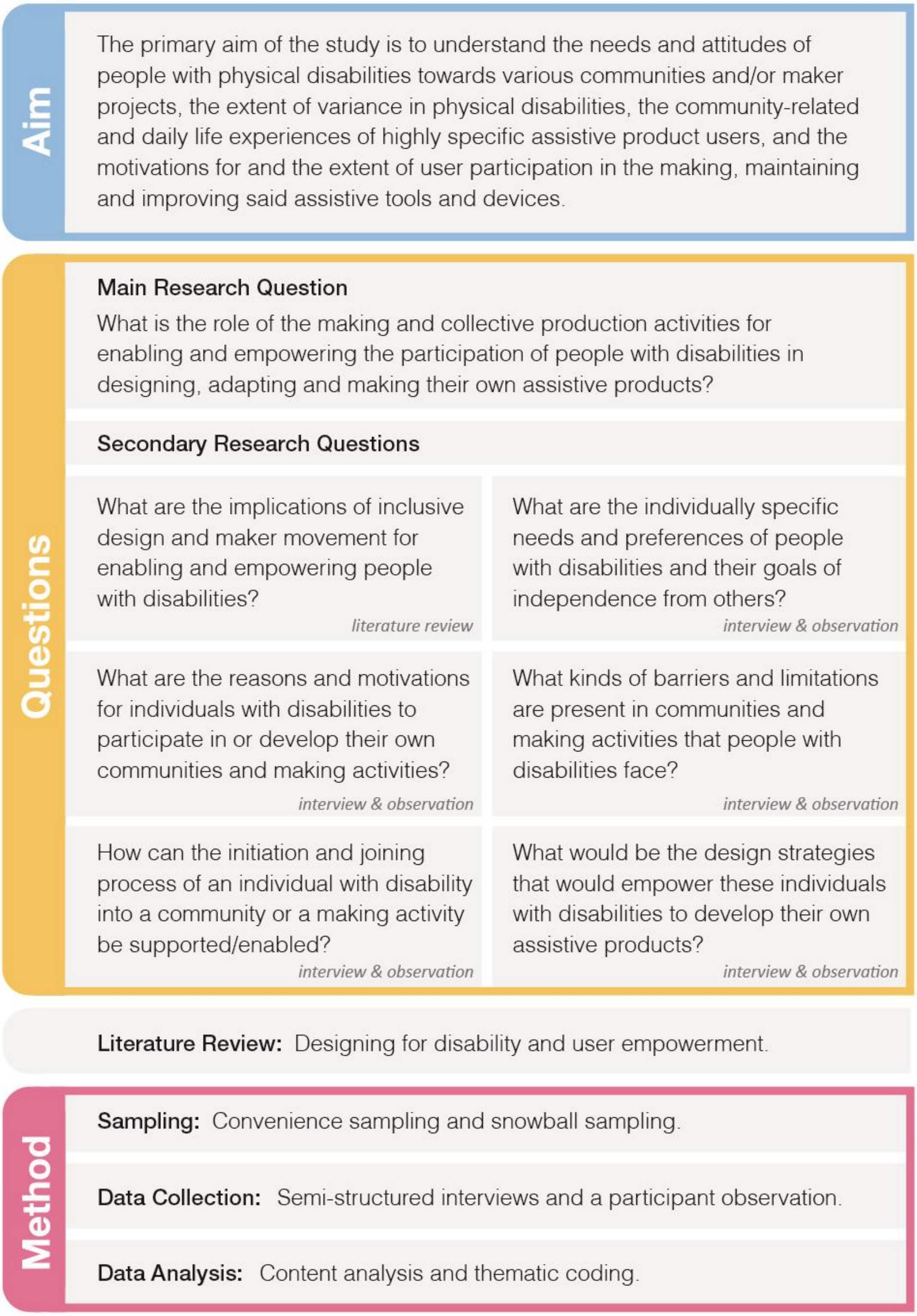
The secondary research questions assisting the main question are:

- What are the implications of inclusive design and maker movement for enabling and empowering people with disabilities?
- *People with Disabilities:* What are the individually specific needs and preferences of people with disabilities and their goals of independence from others?

- *Communities, Social Activities & Built Environments:* What are the reasons and motivations for individuals with disabilities to participate in or develop their own communities and making activities?
- *Communities, Social Activities & Built Environments*: What kinds of barriers and limitations are present in communities and making activities that people with disabilities face?
- *Communities, Social Activities & Built Environments:* How can the initiation and joining process of an individual with disability into a community or a making activity be supported/enabled?
- *Assistive Products, Making Activities & Environments:* What would be the design strategies that would empower these individuals with disabilities to develop their own assistive products?

The research questions are shown below, together with the aim and the methodology of the research in Table 1.1.

Table 1.1 Organization of the study.



Aim

The primary aim of the study is to understand the needs and attitudes of people with physical disabilities towards various communities and/or maker projects, the extent of variance in physical disabilities, the community-related and daily life experiences of highly specific assistive product users, and the motivations for and the extent of user participation in the making, maintaining and improving said assistive tools and devices.

Questions

Main Research Question

What is the role of the making and collective production activities for enabling and empowering the participation of people with disabilities in designing, adapting and making their own assistive products?

Secondary Research Questions

What are the implications of inclusive design and maker movement for enabling and empowering people with disabilities? *literature review*	What are the individually specific needs and preferences of people with disabilities and their goals of independence from others? *interview & observation*
What are the reasons and motivations for individuals with disabilities to participate in or develop their own communities and making activities? *interview & observation*	What kinds of barriers and limitations are present in communities and making activities that people with disabilities face? *interview & observation*
How can the initiation and joining process of an individual with disability into a community or a making activity be supported/enabled? *interview & observation*	What would be the design strategies that would empower these individuals with disabilities to develop their own assistive products? *interview & observation*

Literature Review: Designing for disability and user empowerment.

Method

Sampling: Convenience sampling and snowball sampling.

Data Collection: Semi-structured interviews and a participant observation.

Data Analysis: Content analysis and thematic coding.

1.3 Significance of the Study

The studies involving maker movement are largely in the Human-Computer Interaction (HCI) literature, as well as in design. Maker movement and its relationship with disability is a well-recognized field of research (Ellis et al., 2020; Alharbi et al., 2020; Hofmann et al., 2016). However, most studies investigate maker activities and projects in which the people with disabilities are participating as users who are giving their feedback and experience as input into the making process (Rogers & Marsden, 2013). The investigation of the cases where the members with disabilities are active makers is a relatively new focus of research that gained acceleration in recent years. To illustrate this, Bosse and his colleagues (2018) investigated a project where people with complex disabilities are involved in 3D printing products in a makerspace, such as cup holders, can openers, wheelchair adaptations, and prosthetic arms. The study focuses on the accessibility of the physical maker spaces, but gives less importance to personal problems and experiences of members with disabilities of maker communities. Other studies involve the participants with disabilities in the making process via a workshop environment for a short term that aims to teach the participants maker technologies like 3D printing and laser cutting (Meissner et al., 2017), or investigate non-disabled teachers' making activities in an inclusive school of students with disabilities (Vandenberghe et al., 2022). Authors of the latter research also acknowledge that their findings are affected by the context of a developed nation and may not be generalizable to lower-income contexts (Vandenberghe et al., 2022). There is a lack of research on the personal journeys that people with disabilities take in communities and making activities, including their motivations, barriers, and interactions.

In light of this review, it can be argued that the focus and the aims of this thesis study are directed at a significant gap in the literature. This research concentrates on maker activities from the personal perspectives of people with disabilities, particularly in the developing country context of Turkey. Although there is no consensus on the definition of a developing country, it refers to countries with a lesser overall economy, lower income per capita and life expectancy (O'Sullivan & Sheffrin, 2003). As what it means to be empowered varies between people and contexts (Zimmerman, 2000), investigating the perspectives on a personal level and in a specific socio-economic context can prove to be a valuable addition to the literature. Examining the disability-related and maker communities and their activities through the lens of empowerment can allow this study to contribute to; empowering people with disabilities by defining the current barriers in maker communities, improving the involvement of people with disabilities in the production of their own assistive tools by generating insights for developing disability guidelines aimed at maker communities.

1.4 Thesis Structure

This thesis is organized into five chapters:

Starting with the *Introduction* chapter, which briefly explains the concepts related to the study, its aims and goals, the research questions, and the significance of the study.

The second chapter *Literature Review* presents an in-depth investigation of the literature related to the aims and goals of the study for laying out the context in which the research takes place. The review initially explains the approaches in designing for disability (e.g., universal design, inclusive design, participatory design), then continues with the design research on people with various special needs. Following this, the notion of disability in the context of Turkey is investigated, then associations and members’ involvement is explained. The review also looks into user empowerment literature, after which the relevance of the maker movement is discussed. It finalizes with current design research examples on maker movement and empowerment.

The third chapter, *Methodology*, details the research methods utilized in this study. The chapter starts with explaining the research stages and the sampling methods for the field research. It continues with describing the participants' disabilities and products, then the recruitment strategies are explained. The methods for collecting data and its details are looked into. After going through the data analysis methods in detail, the chapter finishes with the credibility of the study, ethical considerations, and future recommendations on research methodology.

The fourth chapter, *Findings*, provides detailed explanations for the results of the data analysis and defines three main themes: *People with Disabilities*; *Communities, Social Activities & Built Environments*; and *Assistive Products, Making Activities & Environments*. It begins with explaining the individually specific disabilities of the participants and their goal of independence from others, then moves on to the personal and organizational networks of people with disabilities and the exchange of information in these networks. Finally, the dimensions of assistive products and their making activities are discussed in relation to the involvement of the participants in these activities. Each theme provides their relevance to user empowerment and design considerations before moving on to the next.

The last chapter, *Conclusions*, connects the findings of the study to the related literature and research questions, providing insights into the current barriers for communities and making activities and suggestions for making these problems areas more empowering for people with disabilities. Lastly, the chapter explains the limitations and provides recommendations for further research.

CHAPTER 2

LITERATURE REVIEW

This chapter investigates the literature related to the aims and goals of the study. The literature is reviewed under two main categories: *design for disability,* which includes design approaches and research examples, and *user empowerment,* which includes the theory of empowerment and the relevance of maker movement.

2.1 Design for Disability (Design for Special Needs)

The literature regarding design for disability includes the related approaches and definitions, definitions of various disabilities, and design research examples.

2.1.1 Diverse Approaches and Definitions in Design for Disability

The act of designing products, services and solutions while maintaining a specific focus on people with disabilities, shortly designing for disability, can be encountered in various forms and under various definitions throughout design and accessibility literature. While some of these definitions have been used interchangeably, some could function as umbrella terms that include multiple sub-terms. The extent of how much a certain terminology includes and overlaps the others varies considerably between different cultures, professions and contexts, with no definitive consensus (Persson et al., 2015). Consequently, the lack of such defined borders in designing for disability terms can cause confusion and uncertainty while deciding on the aims and the scopes of design projects and research studies in this field.

In order to better specify the scope of this particular research study, several clarifications and definitions should be provided on certain terminologies which are being used in designing for disability and accessibility literature. The terms that are being investigated are; *design for all, universal design*, *inclusive design*, *user-sensitive inclusive design*, and *participatory design*.

2.1.1.1 Design for All

One of the most widely used accessibility terms is design for all, because of its simplicity and applicability to various contexts and professions, such as product design, built environment, policy making, etc. . In The Stockholm Declaration, The European Institute for Design and Disability (EIDD) (2004) states this definition: "Design for All is design for human diversity, social inclusion, and equality." The declaration's target of giving everyone equal opportunities on any designed product, system, or environment is also the widest aim that can be set (EIDD, 2004).

2.1.1.2 Universal Design

NC State University, The Center for Universal Design coins the definition of universal design as "The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (1997). After design for all, universal design is relatively one of the widest definitions amongst similar terminology. Thus, to specify their definition further, the researchers at The Center for Universal Design also listed a set of principles for a universal design such as equitable use for people with varying abilities, flexible use, intuitive use, perceptible information, tolerance for error, low physical effort, size and space for approach and use (NCSU, 1997).

It is also suggested in the scope of universal design that when the developments in the fields of technology and design are in line with the needs of people with physical limitations, all of the users with varying abilities benefit from the results, not only those in specific user groups (Antona & Stephanidis, 2019).

An example of a universal design solution that fits the principles offered by NCSU could simply be a door handle, a United States-based company that produces doorknobs developed ergonomic knob series that aims to help the elderly exert minimal physical effort while opening doors. As seen in Figure 2.1, the design solution eases the elderly users' experience with low physical effort, while still being intuitive and suitable for people of all abilities.

Figure 2.1. Door handle in accordance with the principles of universal design.

Note. Retrieved from *SOSS Door Hardware*, by SOSS, 2022 (https://www.soss.com/ultralatch-product-overview/). Copyright 2022 by SOSS Door Hardware.

2.1.1.3 Inclusive Design

Terminology with similar goals can be developed under different names because they originated in different locations (Turhan et al., 2020). While universal design is originated in USA, the term of inclusive design was first defined in the UK. British Standard on Managing Inclusive Design states the term as:

> “The design of mainstream products and/or services that are accessible to, and usable by, as many people as reasonably possible on a global basis, in a wide variety of situations and to the greatest extent possible without the need for special adaptation or specialized design” (BSI TBSI, 2005, as cited in Persson et al., 2015, p.509).

Compared with the universal design definition, inclusive design’s definition is more accepting of the limitations apparent in designing to the greatest extent. Fletcher (2006) states that inclusive design aims to eliminate dividing barriers that result in unnecessary struggles and allows for equal participation from anyone on their own assuredly.

Figure 2.2. Inclusive work environment of the wheelchair user Participant 13.

As shown in Figure 2.2 above, an inclusive design allows users of all abilities to experience equal levels of interaction. For example, one of the interviews during the field study was done in the workplace of *Participant 13*. The computer table has enough height and clearance in the space under it for the electric wheelchair, but it can be easily used with a regular office chair as well. The cupboards also have low-height drawers for easy access. There are higher file cabinets in the same room for storing more documents, but an inclusive approach to the designing of the room and the placement of the products allowed the wheelchair user to work as comfortably as her non-disabled coworkers.

2.1.1.4 User-sensitive Inclusive Design

The term User-sensitive Inclusive Design (USID) is developed by a research group, inspired by the widely known design term User-centred Design (UCD); they propose that the UCD approach needs modification when dealing with disabled users. The research group points to the elderly as users and argues that the amount of variance in the abilities of elderly people can not be covered accurately with representative user data to center the design process. The focus on the word inclusive accepts the fact that it is not realistic to design with the consideration of all types of elderly user problems and disabilities (Gregor et al., 2002).

2.1.1.5 Participatory Design

Originated from the 1970's Scandinavian workers' demands about the developing technologies they were using, participatory design was formed to bridge the user's expert knowledge with outside technical expertise, and it can be defined as:

> "Participatory Design (PD) represents a new approach towards computer systems design in which the people destined to use the system play a critical role in designing it" (Schuler & Namioka, 1993, p.xi).

Because of its information technology origins, the initial definition of participatory design requires a broader approach that can be applied to the fields of design and research, as Spinuzzi (2005, p.164) explains:

> "…to iteratively construct the emerging design, which itself simultaneously constitutes and elicits the research results as co-interpreted by the designer-researchers and the participants who will use the design."

The user-focused methods of participatory design become more crucial as the products and services are getting more specialized, and require more user expertise to develop. Taking the acknowledgments of User-sensitive Inclusive Design (USID) about the high variance of the needs of disabled users into consideration, the participation of the people with different disabilities in the design processes of the very products and services they use themselves seems to be highly essential. In addition, it should also be noted that the level and the nature of these users' involvement in the design process will vary significantly depending on the personal characteristics of their disability which is unique to each user (Geyh et al., 2011). For example, while a crutch user who has an irregular gait (the walking pattern or form) would have no problem taking the role of a designer in a participatory design workshop, a wheelchair user with a strong speech impediment (e.g., people with cerebral palsy) might require further support and tools to engage them in the design process and to transfer their knowledge.

As shown in Figure 2.3. people can have disabilities at varying levels, which would require different design considerations to include them (Goldsmith, 2007). The optimistic universal design aims for the pointer D to include all users with their needs. However, as Goldsmith (2007) points out, not every product or environment is suitable for the pointer D approach. Some designers can utilize B or C approaches, which offer various levels of inclusion for different people.

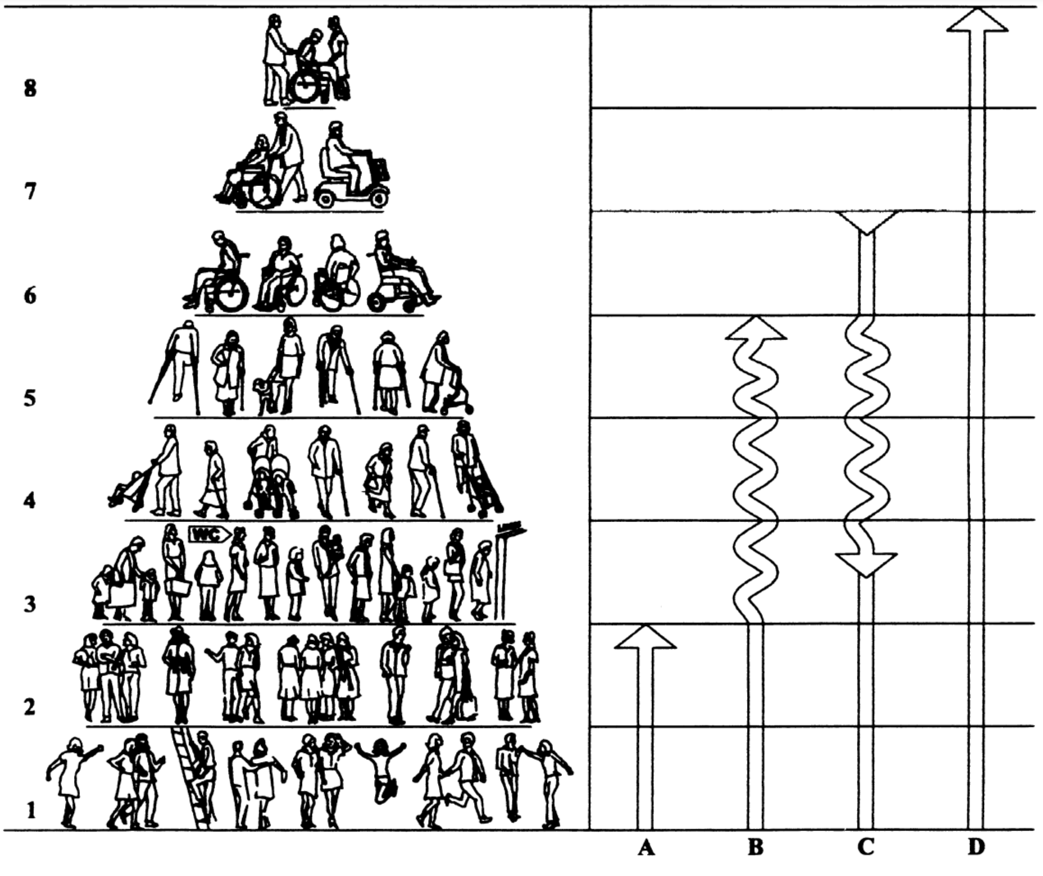


Figure 2.3. The universal design pyramid (Goldsmith, 2007).

Overall, this thesis study focuses primarily on inclusive design as it has realistic standards and goals for design considerations compared to optimistic aims of designing for the whole population, and participatory design as the approach allows for understanding the individually specific needs of users to the best extent.

2.1.2 Users with Special Needs

User groups and their varying levels of abilities and needs shape the design and research processes that involve them. Although possibly changing its scope in different contexts and not having a clear definition for the term, some of these user groups have special needs, which mostly result from their low-level abilities, impairments, or disabilities (Wilson, 2002).

In this thesis research, specific user groups with special needs are chosen to focus the research area on users who are more likely to use physical assistive products, which can provide rich design-related insights. The investigated user groups are; people with cerebral palsy on varying levels, people who have genetic paraplegia, amputees who have lost various limbs, and actively participating paralympic athletes who have different forms of disabilities. Although the types of physical assistive products that these user groups vary, they can be mainly categorized as; mobility products such as wheelchairs and crutches, accessibility solutions such as ramps, convenience solutions such as straws, and specific paralympic sports products such as para-archery triggers and para dance chairs.

In order to better understand the needs and insights of the users with special needs, each of these user groups would require further explanation of their characteristics. This would also help us identify design-related problems and opportunities through analyzing existing design research studies and examples within the research context.

2.1.2.1 Cerebral Palsy

Cerebral palsy (CP) is an unchangeable neurologic condition which occurs if the brain sustains an injury during the process of cerebral development. This condition can occur with an injury before, during, or after birth, as it takes two years for the brain to complete development (Krigger, 2006). Clinically, individuals with cerebral palsy mostly have spastic symptoms, which cause involuntary tightening of muscles, but depending on the time of the brain injury and the specific location in the brain, highly varying types and levels of spasticity occur on the body (Miller, 2005). In other words, each individual with CP has a different and unique type and level of physical disability. This uniqueness of every individual case of CP makes it challenging to provide general assistive solutions that help with each user’s needs (Rosenbaum et al., 2006). However, this can also be argued as the reason for the strong motivations and efforts for CP that can be seen in the fields of education and design research.

2.1.2.2 Paraplegia

Hereditary spastic paraplegias (HSPs) are a heterogeneous group of monogenic neurological diseases. Up to seventy-eight genes are responsible for various types of HSPs (Shribman et al., 2019). Consequently, there is considerable variance in the level of physical disabilities and clinical effects caused by HSPs (Fink, 2006). The physical symptoms include differing levels of increasing irregularity in gait, slowed motor development in childhood, spasticity which is the uncontrolled tightening or twitching of muscles, weakened limbs, and lowered ability to sense vibrations, and seizures. Because of the initial similarity of these symptoms, it might be mistaken for cerebral palsy (Shribman et al., 2019).

2.1.2.3 Amputees

Amputation of a person’s limb(s) either in the lower body or upper body may be required to be done for various reasons; congenital disorders (i.e., birth defects on either the whole or parts of limbs), cardiovascular complications such as gangrene, stopping the spread of cancer on a body part, after physical trauma from traffic/work accidents or as a war injury (Staats, 1996). In addition, depending on the time of the amputation of the limb(s), amputees either adapt to live with physical impairments and disabilities at a certain point of their life, or have these limitations to their bodily functions from birth (Ziegler-Graham et al., 2008). All these factors make amputees a highly varying user group that requires many different design considerations specific to their own cases.

2.1.2.4 Paralympic Athletes

An encompassing user group that can have members from all the groups mentioned above is the paralympic athletes who perform and compete in various sports branches individually or in a team. The reasons for investigating this user group as a separate one are; firstly, because of the highly particular and specialized nature of the assistive products they use during their specific sports activities, and secondly, because of the possible effects of their sports-related experience on their daily life practices and their regular assistive product usage.

The rising popularity and developments in paralympic sports over the last decades can be partly attributed to the positive effects of sports for disabled people. Physical activity for disabled individuals is proven to be highly critical for their overall health and wellbeing (Wilhite & Shank, 2009; Ives et al., 2021). In addition to the benefits of physical activity for the disabled, improving sports activities and eliminating the disparities in sports-related opportunities are not just important for disabled individuals, but also for general public health as well (Smith et al., 2019). These mental, physical and social positive effects of disabled sports are also supported by the personal experiences of disabled individuals who are actively involved in sports activities (Wilhite & Shank, 2009). Wilhite and Shank (2009) exemplify these personal experiences in their cases such as; a person who lost a leg and started participating in dancing to keep a healthy body and exercise, or a sportsman in a wheelchair whose motivation to keep involving in sports is mainly being fit enough for controlling his wheelchair to have social independence.

2.1.2.5 Design Research for Users with Special Needs

There have been numerous design research studies in which the user group in focus were people with special needs. Naturally, the types of the specific disabilities that a research study chooses to focus on affect their methods. For example, while a study on physical disabilities could be more interested in the physical functions of assistive products, another study in which the focus is on people with intellectual disabilities and learning difficulties could have a different approach and focus of the investigation.

A particularly insightful study as part of a doctorate thesis from the field of engineering and computer science with a broad user scope involves people with disabilities, their families, maker communities, disability services organizations, and designers. It is a significant example of design research focusing on people with special needs (Rajapakse et al., 2018). Although the researchers include intellectual disabilities in the study as well, the design considerations they employ and the findings they reach during their co-design sessions with the users (see Figure 2.4) are also applicable to physical disabilities, as one of their participants has cerebral palsy together with other impairments.

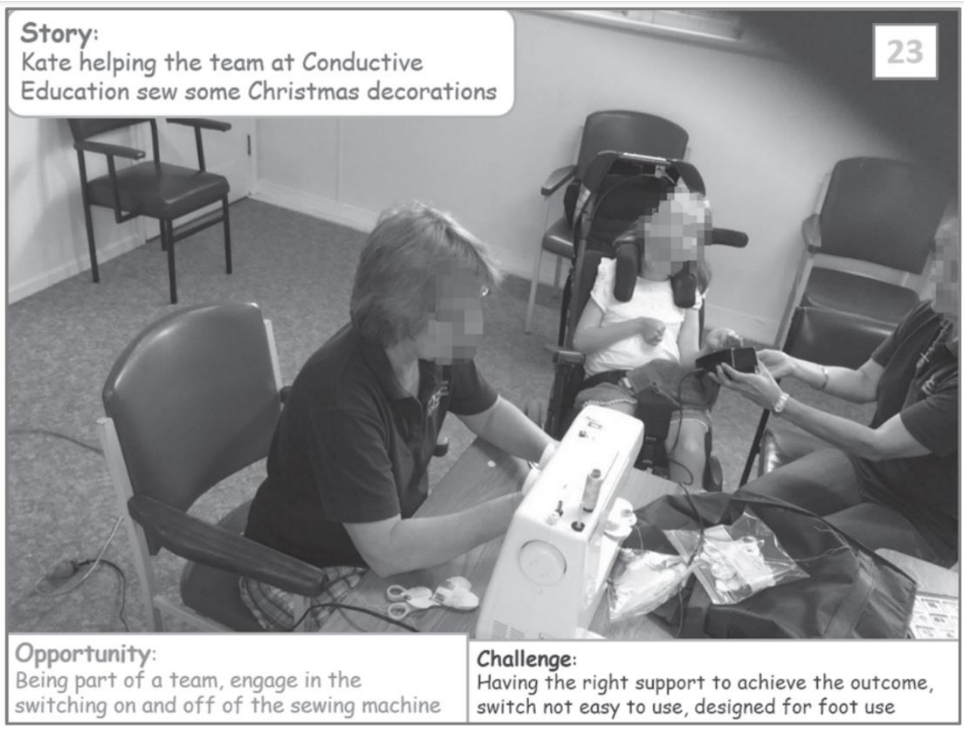


Figure 2.4. An instance of the researchers'(left and right) participatory sessions with the user (middle).

The study found many insights into the varying motivations and needs of all those stakeholders in such collaborations. The members of maker communities and the students who are engaged in this activity as part of their education are on the making side of the assistive products that are meant for the individual with a disability. On the other side are the individuals with the disability, their families, and the organizations that provide the collaboration with the making side. For example, because the students are participating in this process as a part of their university course which would have an eventual assessment, they require a clear explanation of the project and the expected result in the form of a brief in the beginning. Additionally, the makers were involved by their own making-related interests and stated their motivation to keep participating would be present only if the collaboration process was in line with their interests. Meanwhile, the individuals with disabilities and their families were expected to provide their personal experiences and time without knowing whether the process would create a beneficial result for them in the end.

Later on, the researchers also investigated further the motivations, limitations, and how to improve this collaboration between various stakeholders of people with disabilities, students, and makers (Rajapakse et al., 2019). Their study revealed that the main drivers for the making side to participate were the education and the act of participating itself, instead of the intrinsic motivation of helping and improving the lives of other people. Thus, it can also be argued that the students don't have an awareness of the potential impact of their project in the initial phases of their education project, and that the lack of such intrinsic motivations might have led the makers to choose cases of individuals that had disability-related needs which were easier to work with considering the maker’s existing skillset and knowledge. Because Rajapakse and his colleagues (2019) also report that matching the interests of the maker and the person with a certain type of disability was required for the process to work.

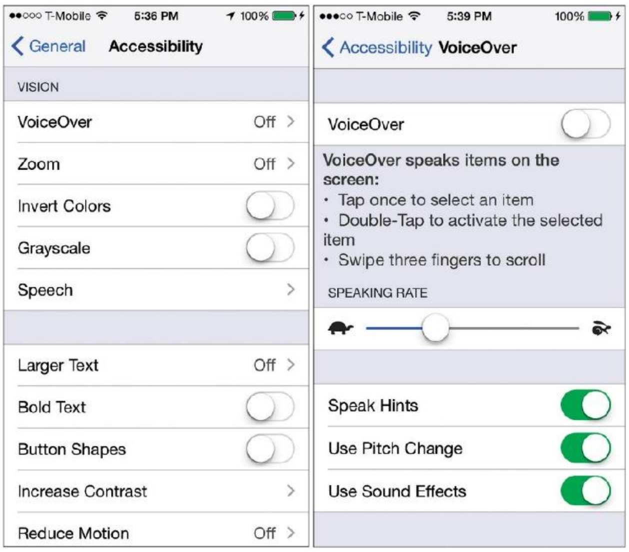
The key finding of their overall study is the concept of, as they define, *personal infrastructuring*:

> “The assembling of services, technologies and people to support a person with different cognitive and sensory abilities to live well and be more self-determined, to capture a broader design perspective on the life of a person with a disability than existing codesign approaches” (Rajapakse et al., 2018, p.286).

To lead a better life, creating this personal infrastructure (both material and social) is also crucial for special needs groups with physical disabilities such as people with cerebral palsy or paraplegia, amputees, and paralympic athletes.

As a design insight, during their study, the researchers developed “design artefacts such as user profiles and video stories to support communication, mutual learning, need finding and need expression” (Rajapakse et al., 2018, p.277). These artefacts, such as video and photo stories (see Figure 2.4) are used as intermediaries during the co-design activities and are reported to be additionally useful for participants' *personal infrastructuring* (Rajapakse et al., 2018). The effectiveness of this approach can be an example for design researchers in working with people with disabilities.

Another example of a design research study that has designing for disability as its focus is Ladner's (2015) theoretical investigation on the possible next step for designing for disability. Ladner explains the different approaches in accessibility research, going through with the example of a screen reader starting as an additional accessibility solution for existing hard to access technologies. Then, he argues that including these kinds of accessibility solutions as built-in parts of the designed products would raise them to the universal design status (see Section 2.1.1.2), exemplified by the VoiceOver function of the iPhone (see Figure 2.5).



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< General **Accessibility**

VISION

VoiceOver Off >

Zoom Off >

Invert Colors ○

Grayscale ○

Speech >

Larger Text Off >

Bold Text ○

Button Shapes ○

Increase Contrast >

Reduce Motion Off >

●●●○○ T-Mobile 5:39 PM 100%

< Accessibility **VoiceOver**

VoiceOver ○

VoiceOver speaks items on the screen:
- Tap once to select an item
- Double-Tap to activate the selected item
- Swipe three fingers to scroll

SPEAKING RATE

Speak Hints ●

Use Pitch Change ●

Use Sound Effects ●

Figure 2.5. The built-in accessibility feature VoiceOver in an iPhone.

Ladner (2015) then moves on to the need of designers to interact with the users for developing accessible designs, especially for people with disabilities, explaining the concept of human-centered design and participatory design (see Section 2.1.1.5) as strategies for understanding the user groups in the design process. He then criticizes the level of inclusion that the users get during the design process of these approaches, emphasizing that it is not enough to involve the users only in the testing and designing stages and that they should also be involved in all stages including the analysis and prototyping stages (see Figure 2.6).

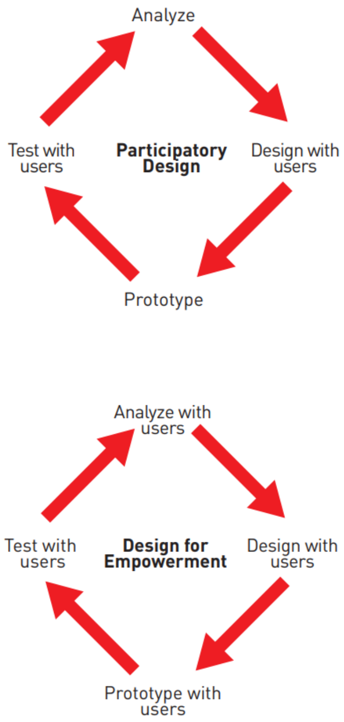


Figure 2.6. The inclusion of users in design stages.

Ladner (2015) defines this more inclusive design approach as *design for empowerment*, arguing that the extended involvement of users is needed as they are the most affected party in the process. He states two prerequisites for achieving design for empowerment, namely *self-determination* and *technical expertise*. The concept of self-determination requires the users to "have control of, and are not just passive recipients of, technology designs intended for them" (Ladner, 2015, pp.27-28). He explains the term technical expertise as the need for users to be proficient in technical aspects so that they can be a part of every design stage, allowing the users to provide a solution for their own problems related to accessibility.

The inclusive approach of design for empowerment is in line with the aims of this thesis study as well, as the users with disabilities need to be involved in all aspects of the design process so they can reach accessible solutions that meet all their needs fully. The concept of empowerment and how it relates to design and disability is investigated further under *User Empowerment* (see Section 2.2).

2.1.3 The Notion of Disability in Turkey

The personal experiences of disabled individuals are strongly shaped by the context of their daily lives. The context in question could be regarding the assistive products they use, the disability regulations and policies they are subjected to, associations and disability service organizations they are involved in, and the barriers and opportunities they face with. Thus, to better analyze the personal experiences of the participants of this study, the notion of disability in the context of Turkey needs to be examined in the first place.

2.1.3.1 Regulations and Policies

There are various regulations and policies adopted by the state regarding the disabled population, categorization of their disabilities, their rights, and privileges.

According to the Turkish Statistical Institute (TÜİK), the disabled population is categorized under six groups: difficulty in *sight*, difficulty in *hearing*, difficulty in *speaking*, difficulty in *walking and using stairs,* difficulty in *holding/carrying items*, and difficulty in *learning* (TÜİK, 2011). Because the categorization is not based on specific disabilities but on difficulties in bodily functions, the groups that are in the scope of the thesis study would be the ones having difficulty in *walking and using stairs*, and difficulty in *holding/carrying items.*

In terms of disabled people’s employment, Turkey has followed the United Nation’s *Convention on the Rights of Persons with Disabilities* since 2007, recognizing that a person with a disability has the right to *work on an equal basis with others* (Assembly, 2006). Additionally, starting from 1971, both public and private employers must have %2 of their workforce as disabled workers, which later increased to %4 (Turkish Disabled and Elderly Services General Directorate, 2022). By 2011, %22 of the disabled population were actively employed, considerably lower than the general employment rate of %52 (TÜİK, 2011).

There are also several privileges in policies for people with disabilities, such as insurance help for women with disabled children, free public and school transportation, tuition waivers according to the degree of disability, disability wage, home care payment, right to have rehabilitation center services, and tax reduction (Turkish Disabled and Elderly Services General Directorate, 2022).

2.1.3.2 Associations and People’s Involvement

Turkey has a rich non-governmental organization (NGO) pool in terms of associations aimed at people with various disabilities, with a total number of 1.354 associations and their branches related to disability currently registered as active in Turkey (DERBİS, 2022).

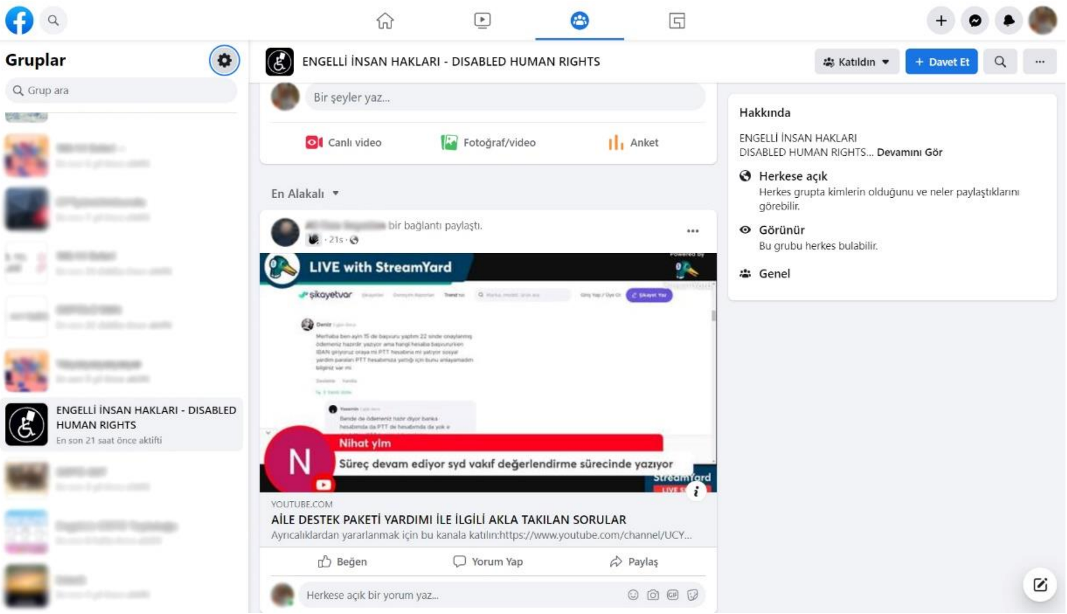
The high number of disability associations in Turkey is also matched with a considerable amount of the general population with at least one form of disability. Looking at the data gathered from the last official population study done in 2011 by TÜİK, the population rate of people with at least one disability was %6.9, which roughly translates to more than 4.75 million disabled people countrywide (TÜİK, 2011). Since keeping an accurate and up-to-date count of the disabled population is crucial for better disability-related policy-making, TÜİK has also been conducting Turkish Health Research at two-year intervals. The latest and a more accurate research with publicly available data was done in 2019, which reported more in detail that the total population rate of people with mobility disabilities (defined as ‘can’t walk’ and ‘can’t use stairs’) was %13.4, which means slightly more than 11 million people in total have mobility-related disabilities (Turkish Disabled and Elderly Services General Directorate, 2022).

There is no official count for the total number of disability association members nationwide. However, a very optimistic approximation can be made for the sake of comparison, by considering each of the 1.354 disability associations having the same member count as one of the biggest disability associations in Turkey, in this case, Altı Nokta Blind Association with 6000 members (Altı Nokta Körler Derneği, 2022). Even when each association is considered to have 6000 members, it only leads to 8 million disabled people being members. Considering the count of 11 million only takes mobility-related disabilities into account, and the associations include all types of disabilities, it would mean well more than %25 of the disabled population is not involved in associations.

2.1.3.3 Barriers and Opportunities

Looking at the complex ecosystem of Turkey’s regulations, policies and associations related to disabilities, various barriers and opportunities exist for people with disabilities.

Because the unique needs of people with disabilities change with the developing context of Turkey, the disability-related policies and rules are regularly improved and altered. However, this situation results in people with disabilities not being able to keep up with the recent changes in the specific policies, laws, and privileges they might have acquired. To compensate for this lack of new knowledge, online communities are formed by people with disabilities to exchange recent regulative updates and inform each other in a rapid way (Engelli İnsan Hakları - Disabled Human Rights, 2022). Those online communities are independent from established disability associations and institutions, and are maintained by individuals to provide information to other people with disabilities. To illustrate, Figure 2.7 shows an example of an individual sharing a helpful video about social aids that families with disabled members can get inside a Facebook group for disability rights.



Süreç devam ediyor syd vakıf değerlendirme sürecinde yazıyor

AİLE DESTEK PAKETİ YARDIMI İLE İLGİLİ AKLA TAKILAN SORULAR

Ayrıcalıklardan yararlanmak için bu kanala katılın:https://www.youtube.com/channel/UCY...

Herkes grupta kimlerin olduğunu ve neler paylaştıklarını görebilir.

Bu grubu herkes bulabilir.

Figure 2.7. Informing video sharing on a Facebook page related to disability rights (Retrieved from: https://www.facebook.com/groups/120896181254049, May 22, 2022).

In this case, the ease of access and visibility of the social media platforms are seen as an opportunity by people with disabilities to be informed and let others get informed about the latest changes in disability regulations.

In addition to disability regulations, the barriers caused by the lack of knowledge are also present for the disability associations and institutions as well. As discussed in the previous heading (see Section 2.1.3.2), the involvement of people with disabilities in disability-related associations is considerably low, with easily more than a quarter of the disabled population not participating at all. It could be argued that this low participation rate is connected to the fact that people with disabilities don’t have enough knowledge about the associations, the advantages of being involved, and how to initiate participation. There could be a potential opportunity to be seized by the existing disability associations already in significant numbers in Turkey. As the active association statistics take the branches of bigger associations and smaller associations that could be active or inactive in practice (DERBİS, 2022), the credibility and the actual number of associations that a person with disabilities can reach might be lower than expected. It could be suggested that forming federations to group smaller associations with similar disability-related aims would give them more visibility and credibility for gaining new members.

2.2 User Empowerment

The main goal of designing for disabilities should be to empower the people with special needs through the designed products, services, environments, and the act of designing itself. To achieve this goal, what is meant by the term *empowerment* needs to be clearly defined in the first place.

The Oxford Advanced Learner’s Dictionary (2022) defines the term *empowerment* as “the act of giving somebody more control over their own life or the situation they are in,” placing the empowered party in a passive, receiving position. A widely accepted academic investigation of the term in question comes from the psychology literature, the *Empowerment Theory* developed by Zimmerman (2000). In his theory, Zimmerman divides the concept of empowerment into three main elements which involve: firstly, being able to *control and access resources*, then *participating with others*, and finally having *critical awareness of the socio-political environment.* In addition, he underlines that none of these three aspects of empowerment can be evaluated without taking the specific individual and their environment into consideration. Consequently, it is argued that both what it personally means to be empowered and the requirements that are needed to be empowered can change drastically from one individual to another (Zimmerman, 2000). Thus, in this specific study on people with disabilities, each person’s individually specific set of abilities, the assistive products they use, and the social and economic context they live in change their perception and requirements of empowerment.

2.2.1 Maker Movement

A considerable amount of research has been done, not specifically in design but mostly in human-computer interaction (HCI) literature, on the connection between user empowerment and the maker movement. Similar to defining the term empowerment, the relatively new term of maker movement needs to be defined initially to evaluate its potential for empowering the users that are involved in the act of making.

The maker movement can be said to have its origins in the Maker Faire of 2006, which was organized a year after the debut of Make magazine (Dougherty, 2012). Although humans have always been *makers of things*, the recently emerged makers in question utilize the opportunities of technology for producing and communicating their ideas. These makers develop and build original objects on their own by using digital fabrication and craft skills (Lang, 2013, as cited in Meissner et al., 2017).

To better understand what areas and sectors in which the maker movement is producing objects, Millard and his colleagues (2018) present four main activity areas of the maker movement:

- *Digital production*, the makers utilize various computer-aided-design (CAD) software that allows them to design objects in 2D and 3D, which then can be produced physically with a combination of techniques that add (e.g., 3D printing), and/or remove (e.g., milling) material. These techniques mostly use cheap materials which can be obtained in the local area of production, improving the sustainability value of the process.
- *Community awareness platforms* focus on topics of sustainability and raise awareness through collaborative action. These platforms aim to induce behavior change and increase the credibility and self-regulation of the communities. The commonalities of these platforms with the maker movement are generating the information collectively, creating social

networks, and having a first-hand connection with the real-world using Internet of Things. Makers are following a similar trend by generating and using physical objects together in communities.

- *Crafts, do-it-yourself, creative and learning activities* are aimed at people who are inexperienced in tinkering, repairing, or building objects; do-it-yourself approach allows them to *make* without the intervention of experienced makers. The maker movement emphasizes trial and error, active creativity, and the joyful characteristics of the do-it-yourself approach. This creative environment empowers the makers to explore new opportunities and ideas without requiring success at the end of the making process.
- *The creative industries* consist of art, design, music, crafts, architecture, film, fashion, and many more industries. Due to the act of making things is inherently a creative process, the resulting objects and artifacts are supporting and becoming a part of these creative industries.

In the scope of this thesis study, the focuses of activity areas are *Crafts, do-it-yourself, creative and learning activities,* and *Community awareness platforms.* Although activities related to *Digital production* and *The creative industries* are present in the study, they are not as prevalent as DIY and community activities. The reasoning for this approach would be that assistive product users are expected to be more inclined to DIY activities than digital production regarding their abilities and technical know-how. Additionally, the research focus on the personal journeys of people with disabilities in the maker and disability-related communities is directly related to the activity area of *Community awareness platforms.*

The maker movement and its activities in these areas allow the producers to move away from the standard business models and utilize the local materials where their products are being able to be built closer to, and even by their customers, reducing the material waste and the sizes of supply chains (Gershenfeld, 2017). In addition to lowering the environmental footprint of production processes, the maker movement can also bring a drastic social change by generating novel occupations and skills, which can provide a better sense of individual achievement to the people in the maker communities (Millard et al. 2018).

Current research on various maker communities with differing focuses shows that there are several common characteristics of these communities: the first one is the utilization of the 3D printing technology for the production of the objects, the second is the overall novice nature of the makers that allows them to focus more on exploration and initiation of ideas, and lastly, their main motivations for making objects are researching and education (Millard et al. 2018).

A specific group of maker communities with a clear focus on educative motivations are the Fab Labs aiming to create a space for makers to educate themselves on designing and making by using technological and physical tools. Those Fab Labs provide opportunities for students, companies, and the public to learn from each other (Kohtala, 2017). The increase in such grassroots communities is also in line with the trend of manufacturing processes getting more and more distributed (Gershenfeld, 2017). It is also argued that these trends will lead to the formation of wider spread versions of Fab Labs, namely Fab City systems that will help to create circular and resilient communities (Ermacora, 2018).

Today’s maker ecosystem is at the beginning stages of the future with circular economies and distributed manufacturing. Most contemporary makers are still mainly amateurs who aim to build novel products, create for their community, and innovate ideas, with which some makers form new entrepreneurship and start-ups (Millard et al., 2018). Consequently, it would be beneficial for society to create a suitable environment in policy-making for the maker movement’s growth. Steering the industry in this way would help realize the economic, social and sustainability promises of the maker movement (Millard et al., 2018).

2.2.2 Relevance of Making to Empowerment

The act of making is considered to advocate accessibility and wellbeing in relation to disability (Rogers & Marsden, 2013). Additionally, it has been proven that making is supportive of the development of assistive products, including but not limited to; individually tailored prosthetics (Hofmann et al., 2016), accessible keyboards (Ellis, 2020), or tools used in physiotherapy (Alharbi et al., 2020). In other words, improving the customizability and affordability of assistive products and systems for people with disabilities has been put forward as a major promise of the maker movement (Buehler et al., 2015).

The makers of products have been traditionally seen as opposites of their users (Roedl et al., 2015). In the case of users with disabilities, this would mean people who do not have disabilities are the makers of the assistive products that people with disabilities use. Thus, it could be argued that this perspective leads to a disparity between the users' needs and wants, and the design decisions being made on the assistive products. This could be turned into a design opportunity by rethinking the relationship between the meanings of user and maker (Meissner et al., 2017). This opportunity could be seized by designing technologies suitable for additional modifications from the user, which would allow a better possibility for empowerment (Storni, 2014).

Buehler (2016) underlines that the act of making has a high potential for providing empowerment to people who are considered disempowered. This perspective is also supported by the argument that when regular users are proficient in technology, such as makers, they also have a *hacker* understanding of knowledge sharing, which is a crucial element of empowerment (Roedl et al., 2015).

Furthermore, there are also arguments on how the maker movement empowers the assistive products' usage process in addition to the process of their production. De Couvreur and Goossens (2011) argue that products of maker activities might reduce the rate of assistive device users abandoning their products after a certain time period. Also, Rogers and Marsden (2013) state that the number of people who can reach the technology they require increases when the people who aren’t engineers are empowered to design, alter, and create their own assistive products. This empowerment of users with disabilities is seen as likely to solve the problems caused by the *one-design-meets-all assistive products* on the market (Hurst & Tobias, 2011).

Another term that goes hand in hand with the maker movement is do-it-yourself (DIY), for which research suggests that applying the DIY approach to assistive products *democratizes* both the processes of production and design (Tanenbaum, 2013). However, it is also argued that the members of the maker movement are not diverse demographically, which limits their promise of democratization (Meissner et al., 2017). It is observed that a significant portion of the maker community is non-disabled people (Worsley & Bar-El, 2020). This *lack of representation* might be caused by assistive products being highly specialized, and requiring technical expertise, even leading to some researchers advocating for the need of an *assistive technologist* profession (Norrie et al., 2021). As a result, the DIY approach in current maker communities is not do-it-yourself, but do-it-for-others (Hofmann et al., 2019).

2.2.3 Current Research on Maker Movement and Empowerment

The research on assistive products, maker movement and empowerment has been rich in content overall. However, when the scope is narrowed down to people with disabilities acting as makers specifically on their own, the amount of research done is considerably low. This situation is argued to be in contrast with the empowering promises of the maker movement (Meissner et al., 2017). There are several examples of research that is important to note from this small sample of studies with a specific focus.

It has been criticized that the existing assistive products on the market have high cost and that they can’t be adapted to personal user preferences (Rajapakse et al., 2014). *Do-it-yourself assistive technologies* (DIY-AT) approach is aimed to improve these shortcomings. Still, as Buehler et al. (2015) find out, primarily people without disabilities are involved in the actual acts of making in DIY-AT processes. The study showed that the DIY objects are mainly built by makers without disabilities who have the technical knowledge, as part of a personal network that an individual with a disability forms.

Another study on the maker movement by Roedl et al. (2015) thoroughly analyzed more than 190 papers on maker culture, and categorized how empowerment is celebrated under two titles, namely *materially empowered subjects* and *means of social progress.* The former title is about people who are empowered to alter objects and evaluate their materials. Meanwhile, the latter focuses on social enjoyment that the act of making objects, sharing the means to make, and challenging consumerism.

One particularly insightful example comes from a group of researchers that wanted to observe how individuals with disabilities utilize maker infrastructures and technologies for making objects of their own use, and how they relate this making experience with empowerment (Meissner et al., 2017). The researchers in that study try to reach their aim by investigating online maker videos of people with disabilities, making observations in makerspaces, and lastly, conducting their own workshops. That series of workshops, which are called DIYAbilities, involved the participation of users with disabilities who are learning how to utilize digital fabrication methods by creating their individual maker projects. The researchers aim to replicate a real makerspace environment with the necessary tools and equipment. They also underline their efforts to increase the workshop environment’s accessibility to accommodate the participants with various disabilities, which affects not only the physical makerspace but also the tutorials they used in the workshop.

In their study, Meisner et al. (2017) worked with a participant group of varying disabilities such as cerebral palsy, motor and speech impairments, and wheelchair users. Their participant pool is very similar to the sample group of this Master's thesis study, and the insights they gained are also important for this study. They find that their participants with disabilities are all interested in technology with no considerable skill or experience. Thus, as shown in Figure 2.8, the tech-novice participants decided to choose to work on daily-life problems in their own environments that are limiting them.

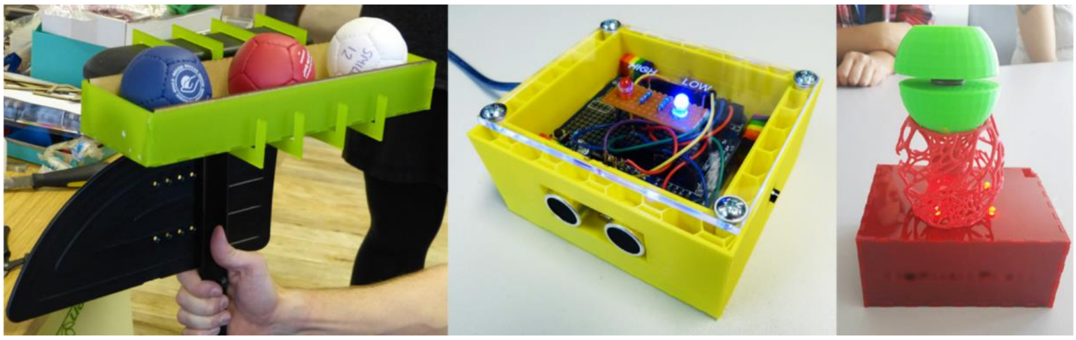


Figure 2.8. The maker projects from the workshop (Meissner et al., 2017).

At the end of their series of workshops, the researchers emphasize four main themes: *Pragmatism and Patience* that the participants show when they are faced with individual problems related to their own specific set of disabilities during the workshop, *Collaboration for Independence* that the participants with disabilities form to reduce their dependence on researchers without disabilities, *Developing New Abilities* which is the aim of most participants so that it would help them be more qualified when applying to future jobs, and lastly *Material Points of Contact* as in the objects that the participants make in the workshop allowing other participants to approach them and start a conversation (Meissner et al., 2017). In addition to these themes, they analyzed the final objects and found out that some participants created their maker projects to take action for their own empowerment, while some participated in enabling other people with disabilities which allows them to become the helper; another participant was just interested in demonstrating his skill in making. This variation leads the researchers to conclude that the act of empowerment appears to be highly subjective for each participant (Meissner et al., 2017).

Recently, another in-depth HCI study on DYI-AT approach is done by Vandenberghe and his colleagues (2022), which is particularly insightful for this thesis because it involves a special school for children with disabilities. In their one-year-long observation study, the researchers investigated the relationship between the assistive technologies that are used in the school, and students and teachers daily.

The researchers argue that the purpose of the study and the sample group they have chosen require them to design the process as a long-term observation while they are volunteering in the school (Vanderberghe et al., 2022). This method seems to allow them to assess the empowering effects of the various technologies, and observe the underlying bigger problems related to infrastructure that would take longer to be apparent from the researcher's perspective (see Figure 2.9).

Figure 2.9. Observation photos showing assistive products and infrastructure (Vanderberghe et al., 2022).

After the observations, their research shows that the empowering potential of the DIY approach (Rogers & Marsden, 2013) is not present in their case study. Then, the researchers argue that without enough infrastructure in place, providing assistive technologies might have excluding and disempowering results (Vanderberghe et al., 2022). They also find out that the teachers' use of maker technologies is not in line with the digital and individualistic maker trends; instead, the teachers are observed to do simple making actions and objects to deal with the lack of infrastructure and resources. In terms of the students, it is observed that their set of abilities, needs, and identities are complicated and multi-layered due to their disabilities being highly individually specific, and their socio-economic levels being varied. Vanderberghe and his colleagues (2022) define this complex educational environment as *heterogeneous and fluid*, resulting in a mixed view when assessing the potential of maker movement on students with disabilities.

To overcome these issues, the researchers suggest that instead of utilizing detailed maker technologies that would require more time and effort from the participants, making use of simpler and quicker methods of adaptative solutions will be more effective at empowering the people involved (Vanderberghe et al., 2022). Although this suggestion is targeted at making activities in an inclusive school environment, it might be logical to apply this approach when designing for the participation of people with disabilities in making activities in all contexts. At the very least, utilizing simpler maker methods would render the making activities more accessible, approachable and adaptable for newcomers.

2.3 Summary

As investigated above, the literature that I am interested in includes the topics of *universal design*, *inclusive design*, *accessibility*, *maker movement*, and *empowerment*. From the literature, it is clear that disability as a whole has a great variation in terms of the special needs of each disability type. Thus, for continuing with the field research, I decided to focus on the intersection between people with physical disabilities and maker communities (see Figure 2.10).

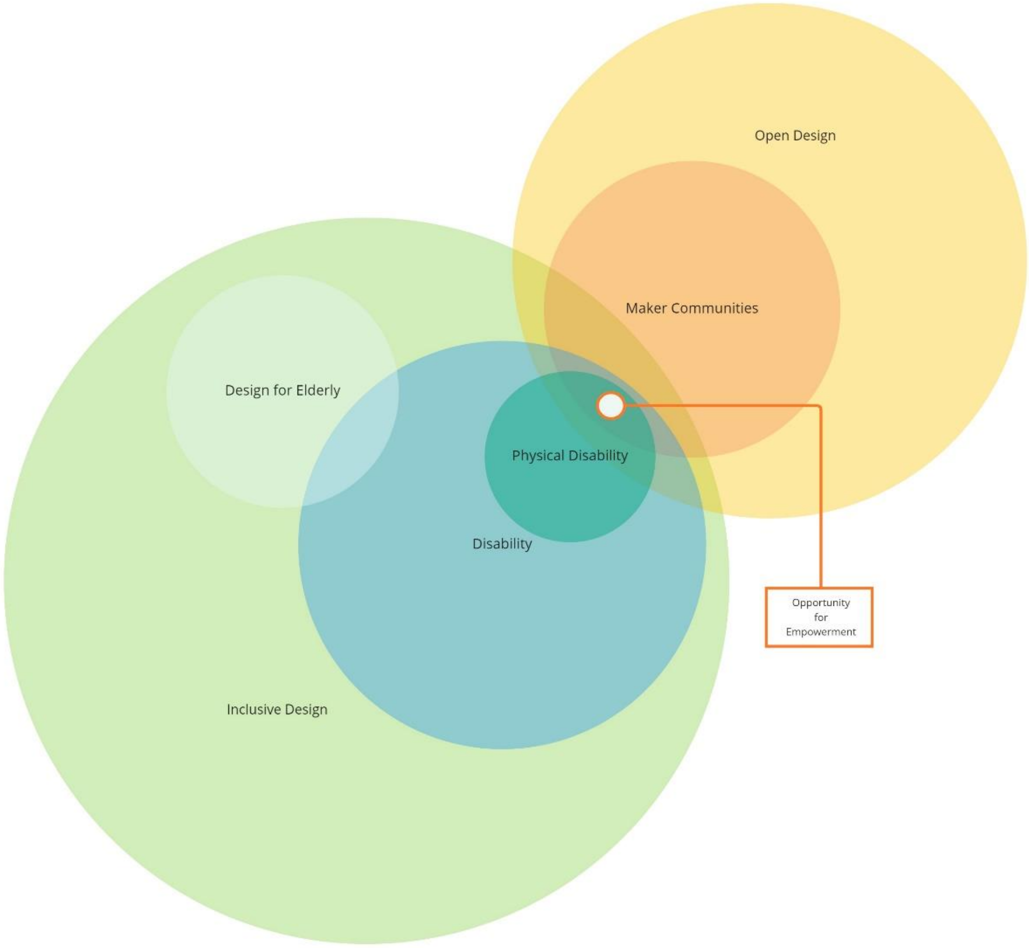


Figure 2.10. Scope of the study.

Consequently, in this study, the intersection of physical disabilities and maker communities is investigated through the theoretical framework of empowerment (See Section 2.2). As discussed above, the well-researched empowering promise of the maker movement is assessed from the statements of field research participants with physical disabilities.

CHAPTER 3

METHODOLOGY

The nature of this master’s thesis is essentially an inquisitive study on the personal user journeys of physically disabled individuals, and their assistive tools and devices. The study aims to clearly understand the extent of variance in physical disabilities, the community-related and daily life experiences of highly specific assistive product users, and the extent of user participation in the making, maintaining and improving said assistive tools and devices. In order to reach these objectives, this thesis study includes the stages of; a *literature review* of the related fields such as inclusive design, universal design, user empowerment, cerebral palsy, and paralympic athletism, a set of *semi-structured interviews* with participants having various types and levels of physical disabilities, assistive products and services, and socio-economic backgrounds, and finally a *one-day-long user observation session* including filed notes conducted in an inclusive high school that is connected to a disability association.

3.1 Motivation for the Study

Qualitative studies are done to understand and depict the subject in their focus (Patton, 2014). The data that is gathered for understanding the subject is of nonquantitative nature, text-based data from interviews and field research notes, visual-based data from photographs and videos, and websites that include human insights on the subject (Saldana, 2011).

In order to understand the subject of disability in this study, I applied a qualitative research approach by analyzing the data gathered during semi-structured interviews with the participants who have various cases of disabilities. By utilizing the disability-related networks of the participants, I was also able to conduct a user observation session in an inclusive high school as well. From the beginning of the field research, I narrowed down the target group of my study to a certain set of physical disabilities, which helped the data to be consistent in terms of the assistive products that were being used by the participants, with enough variation in between them. The decision to focus the research on certain physical disabilities stemmed from the literature review process I started in November 2020.

3.2 Research Methodology

After deciding on investigating physical disabilities and related assistive products, I formally started my field research in June 2021 by conducting in-depth semi-structured interviews with the participants having physical disabilities. The first set of these interviews was completed in the same month with six participants. Then, I did an initial transcription of the interview data, followed by the evaluation of the interviews and the formation of preliminary codes for analysis. The second set of participant interviews started in February 2022 that included seven more participants. The last step of the field research was the one-day-long user observation session done in the only inclusive high school for students with disabilities in Turkey. During the observation, I had the opportunity to attend and observe several classes and ask questions to students and teachers. I transcribed the interview data simultaneously with the field research and started to analyze the field research data in June 2022. The writing of the thesis is also done simultaneously with the research processes and lasted until August 2022.

In this section, the field research phase of the study is explained. First, the sampling methods that were employed to choose the disability types and the participants are discussed. Then, the steps for the recruitment of the participants are explained. Finally, the techniques that are used for the data collection during the field research are discussed.

3.2.1 Sampling

The main sampling technique used in this study is a combination of convenience sampling and snowball sampling. The sampling pool for the participants was selected from three different sources; individual answers to the social media announcements of the study, mailing lists and physical centers of various disability-related organisations and associations, and personal disability-related networks of the initial participants of the study.

Berndt (2020) explains that there are two main sampling techniques: *probability* and *nonprobability* samplings. Although probability sampling allows for more accurate statistical representations, nonprobability sampling is used in qualitative studies focusing on hard-to-reach sample groups, as these groups have small population sizes and statistical analysis would be inaccurate (Berndt, 2020). Because the target population of this study can be considered as a hard-to-reach sample, *nonprobability sampling* is chosen.

Berndt (2020) compares the pros and cons of different nonprobability sampling strategies. The most advantageous sampling strategy to use when researching people who are hard to recruit is *snowball sampling* (Berndt, 2020). As snowball sampling relies on an initial participant, for the recruitment of these participants convenience sampling (Etikan et al., 2016) strategy is chosen.

3.2.1.1 Convenience Sampling

Stratton (2021) explains that *convenience sampling* is mostly used to choose participants that are ready at the moment to get involved in the study. The participants are selected in terms of their proximity to a location or availability in a group. The convenience sampling strategy relies on the active decision to participate from the population in an announced study, thus requiring the participant’s motivation (Stratton, 2021). As this study's participants are a relatively small population, convenience sampling is used through the announcement of the study to reach the initial participants.

3.2.1.2 Snowball Sampling

Snowball sampling works by selecting and reaching out to a small number of the intended target population, who, after participating, assists the researchers in reaching out to more members of the same population (Magnani et al., 2005). Because this study uses a combination of convenience sampling and snowball sampling, the initial participants got involved in the study with their own motivation, meanwhile, the consequent participants are reached out through the personal and social media networks of the initial participants.

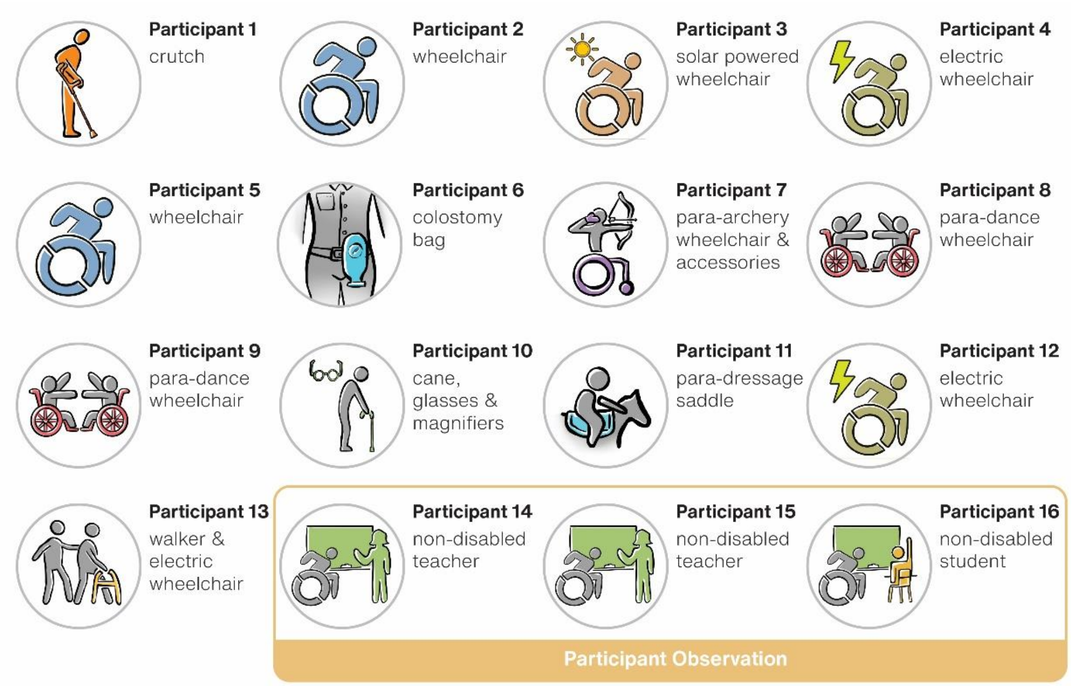
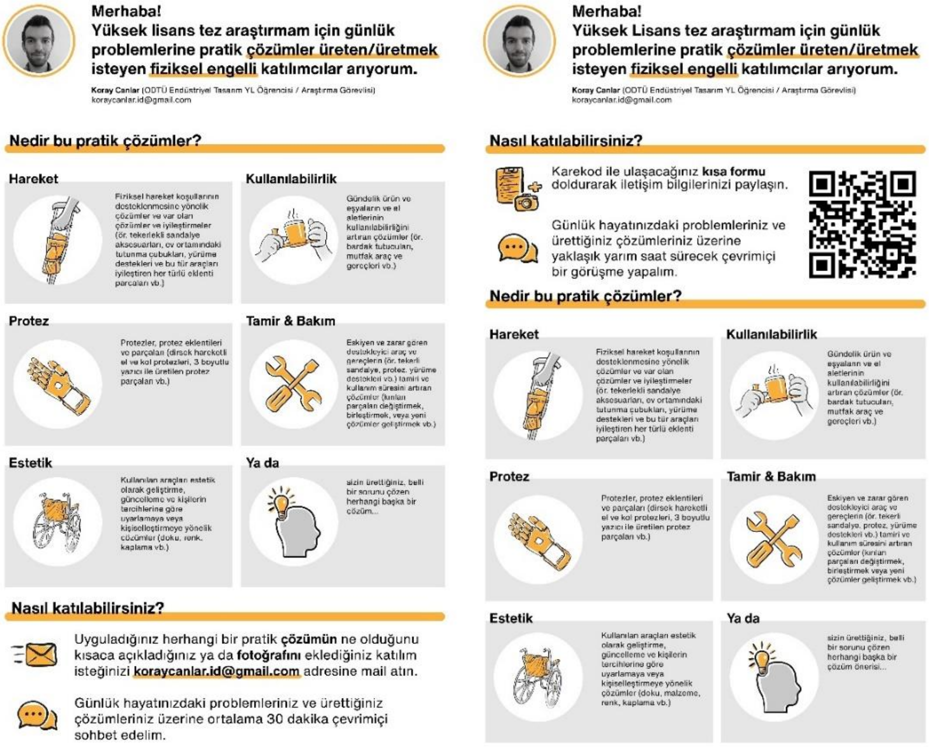


Figure 3.1. The participants and their assistive products.

As it can be seen in Figure 3.1, the snowball sampling started with *Participant 1*, and the consequent participants were reached out by utilizing his disability network, both personally and through his highly active social media account, where he helped to further announce the study. Although the seeming reach of his announcement was similar to the initial announcement of the study itself, it attracted more attention from potential participants as *Participant 1*'s reference was seen as an assurance, proving the effectiveness of the snowball sampling strategy.

3.2.2 Recruitment

For the recruitment of the participants of the study, an initial invitation message was prepared along with a recruitment poster (see Figure 3.2), to be shared both on social media groups (disability-related and unrelated), and with disability associations and organisations which have different types of physically disabled members. For the recruitment of the second set of interviews, the initial poster was revised to increase the visibility of participation-related information (see Appendix A for further variations of the poster).



Merhaba!
Yüksek lisans tez araştırmam için günlük problemlerine pratik çözümler üreten/üretmek isteyen fiziksel engelli katılımcılar arıyorum.

Koray Canlar (ODTÜ Endüstriyel Tasarım YL Öğrencisi / Araştırma Görevlisi)
koraycanlar.id@gmail.com

Nedir bu pratik çözümler?

Hareket
Fiziksel hareket koşullarının desteklenmesine yönelik çözümler ve var olan çözümler ve iyileştirmeler (ör. tekerlekli sandalye aksesuarları, ev ortamındaki tutunma çubukları, yürüme destekleri ve bu tür araçları iyileştiren her türlü eklenti parçaları vb.)

Kullanılabilirlik
Gündelik ürün ve eşyaların ve el aletlerinin kullanılabilirliğini artıran çözümler (ör. bardak tutucuları, mutfak araç ve gereçleri vb.)

Protez
Protezler, protez eklentileri ve parçaları (dirsek hareketli el ve kol protezleri, 3 boyutlu yazıcı ile üretilen protez parçaları vb.)

Tamir & Bakım
Eskiyen ve zarar gören destekleyici araç ve gereçlerin (ör. tekerli sandalye, protez, yürüme destekleri vb.) tamiri ve kullanım süresini artıran çözümler (kırılan parçaları değiştirmek, birleştirmek, veya yeni çözümler geliştirmek vb.)

Estetik
Kullanılan araçları estetik olarak geliştirme, güncelleme ve kişilerin tercihlerine göre uyarlamaya veya kişiselleştirmeye yönelik çözümler (doku, renk, kaplama vb.)

Ya da
sizin ürettiğiniz, belli bir sorunu çözen herhangi başka bir çözüm...

Nasıl katılabilirsiniz?

Uyguladığınız herhangi bir pratik **çözümün** ne olduğunu kısaca açıkladığınız ya da **fotoğrafını** eklediğiniz katılım isteğinizi **koraycanlar.id@gmail.com** adresine mail atın.

Günlük hayatınızdaki problemleriniz ve ürettiğiniz çözümleriniz üzerine ortalama 30 dakika çevrimiçi sohbet edelim.

Merhaba!
Yüksek Lisans tez araştırmam için günlük problemlerine pratik çözümler üreten/üretmek isteyen fiziksel engelli katılımcılar arıyorum.

Koray Canlar (ODTÜ Endüstriyel Tasarım YL Öğrencisi / Araştırma Görevlisi)
koraycanlar.id@gmail.com

Nasıl katılabilirsiniz?

Karekod ile ulaşacağınız **kısa formu** doldurarak iletişim bilgilerinizi paylaşın.

Günlük hayatınızdaki problemleriniz ve ürettiğiniz çözümleriniz üzerine yaklaşık yarım saat sürecek çevrimiçi bir görüşme yapalım.

Nedir bu pratik çözümler?

Hareket
Fiziksel hareket koşullarının desteklenmesine yönelik çözümler ve var olan çözümler ve iyileştirmeler (ör. tekerlekli sandalye aksesuarları, ev ortamındaki tutunma çubukları, yürüme destekleri ve bu tür araçları iyileştiren her türlü eklenti parçaları vb.)

Kullanılabilirlik
Gündelik ürün ve eşyaların ve el aletlerinin kullanılabilirliğini artıran çözümler (ör. bardak tutucuları, mutfak araç ve gereçleri vb.)

Protez
Protezler, protez eklentileri ve parçaları (dirsek hareketli el ve kol protezleri, 3 boyutlu yazıcı ile üretilen protez parçaları vb.)

Tamir & Bakım
Eskiyen ve zarar gören destekleyici araç ve gereçlerin (ör. tekerli sandalye, protez, yürüme destekleri vb.) tamiri ve kullanım süresini artıran çözümler (kırılan parçaları değiştirmek, birleştirmek veya yeni çözümler geliştirmek vb.)

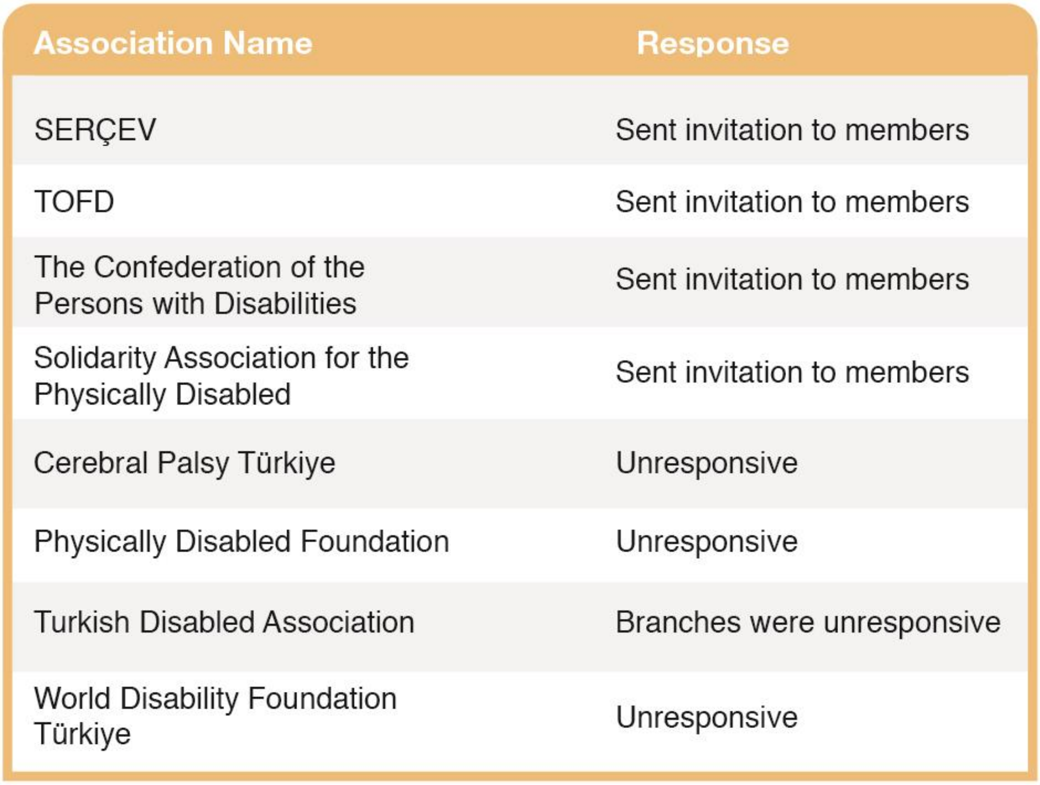
Estetik
Kullanılan araçları estetik olarak geliştirme, güncelleme ve kişilerin tercihlerine göre uyarlamaya veya kişiselleştirmeye yönelik çözümler (doku, malzeme, renk, kaplama vb.)

Ya da
sizin ürettiğiniz, belli bir sorunu çözen herhangi başka bir çözüm önerisi...

Figure 3.2. Recruitment poster for the first set of interviews (left), the poster for the second set of interviews (right).

In addition to sharing the recruitment posters in social media groups and accounts, the recruitment invitations along with the poster were also sent to the key people (e.g., association secretaries, managers, active members) from the disability associations, including, The Association of Children with Cerebral Palsy (SERÇEV), The Spinal Cord Paralytics Association of Turkey (TOFD), The Confederation of the Persons with Disabilities, Solidarity Association for the Physically Disabled. These associations shared the study invitation with their mailing lists of active members. There were also several other disability associations that the invitations were sent to, but they were unresponsive (see Table 3.1).

Table 3.1 Association responses to the recruitment invitations.



Association Name	Response
SERÇEV	Sent invitation to members
TOFD	Sent invitation to members
The Confederation of the Persons with Disabilities	Sent invitation to members
Solidarity Association for the Physically Disabled	Sent invitation to members
Cerebral Palsy Türkiye	Unresponsive
Physically Disabled Foundation	Unresponsive
Turkish Disabled Association	Branches were unresponsive
World Disability Foundation Türkiye	Unresponsive

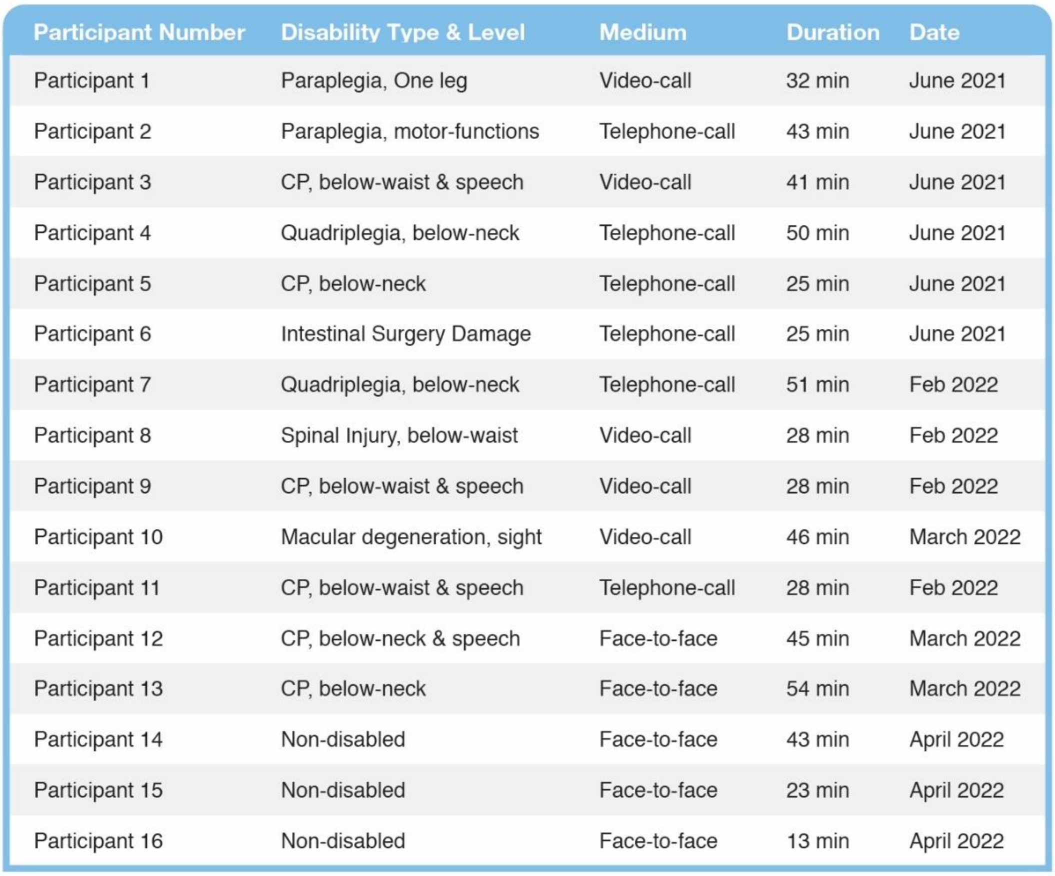
The content of the invitation message can be summarized as explaining to the key person the target participant group and the scope of the study, and asking their members if they are willing to talk about their disability-related experiences, ideas, and dreams (see Appendix B). The association members willing to participate in the study were then asked to fill out an online form for their contact information. However, it was apparent that most participants found it difficult to complete the online form. They opted for directly contacting through the researcher's personal e-mail address and telephone number which were on the poster.

As a result of the convenience sampling strategy, the initial answers for the recruitment understandably came from physically disabled individuals with a relatively higher than average activity and presence on social media networks. Consequently, this allowed the study to utilize the snowball sampling technique by reaching the personal disability networks of these initial social media active participants. Some of these additional participants were informed about the study by the initial participants themselves, while for others, the first participants shared their contact information and a separate invitation was sent to them.

3.2.3 Data Collection

The data collection methods used in this study are semi-structured interviews and a case involving participant observation and field notes. When two sets of interviews and the participant observation are combined, I conducted 13 interviews with participants who have various physical disabilities, one interview with an Information Technologies (IT) teacher in the inclusive high school, and two shorter interviews with a special education teacher and one of the high school students, and each participant is given a number from 1 to 16. Because a large period of the field research process was during the Covid-19 pandemic, most of the interviews were conducted remotely, either through video-conference calls on Zoom, or by telephone calls. The last three interviews and the two shorter interviews were done face-to-face. The remote interviews were video recorded if the participant accepted; the rest of both remote and face-to-face interviews were voice-recorded. All the recordings started after getting the consent of the participants (see Appendix C). For the case of the participant observation, the consent of the high school principal was taken before observing the classes, taking photographs of the products and activities, and speaking with teachers and students. As explained previously, the semi-structured interviews were done in two sets; the first 6 interviews were conducted in June 2021, the second set of interviews started in February 2022, and the user observation was completed in April 2022 (see Table 3.2).

Table 3.2 The nature of the interviews.



Participant Number	Disability Type & Level	Medium	Duration	Date
Participant 1	Paraplegia, One leg	Video-call	32 min	June 2021
Participant 2	Paraplegia, motor-functions	Telephone-call	43 min	June 2021
Participant 3	CP, below-waist & speech	Video-call	41 min	June 2021
Participant 4	Quadriplegia, below-neck	Telephone-call	50 min	June 2021
Participant 5	CP, below-neck	Telephone-call	25 min	June 2021
Participant 6	Intestinal Surgery Damage	Telephone-call	25 min	June 2021
Participant 7	Quadriplegia, below-neck	Telephone-call	51 min	Feb 2022
Participant 8	Spinal Injury, below-waist	Video-call	28 min	Feb 2022
Participant 9	CP, below-waist & speech	Video-call	28 min	Feb 2022
Participant 10	Macular degeneration, sight	Video-call	46 min	March 2022
Participant 11	CP, below-waist & speech	Telephone-call	28 min	Feb 2022
Participant 12	CP, below-neck & speech	Face-to-face	45 min	March 2022
Participant 13	CP, below-neck	Face-to-face	54 min	March 2022
Participant 14	Non-disabled	Face-to-face	43 min	April 2022
Participant 15	Non-disabled	Face-to-face	23 min	April 2022
Participant 16	Non-disabled	Face-to-face	13 min	April 2022

3.2.3.1 Semi-Structured Interviews

Merriam and Tisdell (2015) explain that it is obligatory to conduct interviews to understand thoughts and behaviours we can not observe ourselves or for the observable actions that happened before and can not be repeated. Interviews as part of qualitative research aim to reach those insights, as Patton (2014) claims:

> *Qualitative interviewing begins with the assumption that the perspective of others is meaningful and knowable and can be made explicit. We interview to find out what is in and on someone else's mind to gather their stories.*

As the experiences and perspectives of people with disabilities are fairly unique to them, qualitative interviews were chosen as the main method of gathering data. As noted earlier, the interviews were mostly completed on online platforms because of the pandemic lockdown conditions. It can be argued that the online aspect had both positive and negative effects on the interviews. The disadvantages of remote interviewing were mostly on the topics of setting up the application (Zoom) and the internet connection problems, causing mishearing and the need for repetitions during the interviews. On the advantages, some participants might not be able or prefer to attend a physical meeting because they have severe mobility limitations. Additionally, several other participants were living in other cities or actively in paralympic sports camps, where the logistics of a face-to-face interview would be harder to plan.

Conducting interviews with people with disabilities is a field of interest for the research community. According to Becker and her colleagues (2005), there are several challenges when recruiting people with disabilities as the research subjects. These include people's distrust in the research caused by the unfamiliarity or previous experiences of participation with no positive return, or the need for recruiting through key people that work with disabled communities. There is also a possibility of excluding sub-groups of disabilities further, such as trying to choose people who can give answers through their voice to ease the interview process, leading to the dismissal of valuable insights from people with speech impediments (Becker et al., 2005).

In this study, the remote online nature of the interviews helped the participants agree to meet and familiarize themselves with the study, as it was less effort on their side to attend an online meeting. The problem of recruiting the participant through key people was apparent in the first set of interviews, as some associations were not motivated to pass the invitation on to their members. Although it was challenging to interview some participants with speech impediments during an online meeting or a telephone call, their insights and perspectives proved fruitful and worth the effort for the study.

3.2.3.1.1 Interview Questions

The questions that are asked to the participants during semi-structured interviews (see Appendix D) can be categorized under the topics below:

- *Question for the initial warmup:* their name, defining their disability;
- *Questions related to the community/association:* the name and scope of the community, how they got involved, what roles they have, what activities are done in the community;
- *Questions related to their motivations:* the reason for their involvement in communities, what they gain from activities, whether they participate in making, whether they are involved in any projects;
- *In-depth questions related to assistive products:* what types of products they use, the adaptation they make on the products, and if they are ever involved in the making or modifying activities for their products;
- *Questions about barriers and difficulties:* the problems they faced with their products, their interactions within and outside of the disabled communities, the accessibility problems in their environments;
- *Questions about their dreams and wants:* the features they would like to have in their assistive products, in their environments, the reasons for these wants being unrealized.

3.2.3.2 Participant Observation Session

Merriam and Tisdell (2015) point out that the data gathered from observations can be considered a primary experience with the subject of the research compared to the secondary nature of interview data. They underline that unstructured interviews and quick communications are undeniable parts of observations. This was also the case in this study as well, as the observation in the inclusive high school involved an abundance of conversations.

The participant observation session was completed in April 2022, and arranged through the network of an interview participant who is a founding member of one of the disability associations in Turkey. The inclusive high school is designed explicitly by the disability association to provide co-education with non-disabled and disabled students. Four forty-minute-classes in the high school were attended during the observation day, the teachers were approached after or in-between their class hours for one-on-one interviews, and through their suggestions, a quick interview with a student was planned as well. The observation data is gathered through audio recordings and photographs. The participants were disabled and non-disabled students attending IT and 3D workshop classes, and their special education and class teachers.

3.2.4 Data Documentation

For this study, I used various methods to document the data, ranging from text-based content to audio and video recordings and to visuals of products or observation environments.

3.2.4.1 Data from Interviews and Observations

All the interviews in the first and second set and the participant observation were audio-recorded with the consent of the participants to provide accurate data for analysis. For the cases of interviews through online video calls, video recordings were taken instead. The audio and video recordings allowed me to focus more on the answers and visual elements that were shown by the participants during the interviews.

3.2.4.2 Visuals of Assistive Solutions

The participants answered questions related to the assistive products that they were using, and for some cases they explained certain details on the online video calls, while for others, I asked them to take photos of the products we discussed after the interview. Some participants talked about older products and details they used and provided me with rough sketches instead, which I recreated for visual communication (see Figure 4.3). Also, some participants were active on social media and personal blogs, so I also utilized those accounts and websites to gather visuals, after getting consent from the participants.

3.2.5 Data Analysis

The data analysis for this study includes two stages: the transcription of the audio recordings gathered from semi-structured interviews and the user observation, and the analysis of the transcribed data. Kvale (2007) states that “The more the analysis is undertaken in the early stages of an interview investigation, the easier and the more qualified the later analysis will be.” In accordance with this notion, I started to do an initial analysis of the interview data after the first set of six interviews. This first glimpse into the data allowed me to better direct the next set of interviews to the field of interests that better suits this study. The participants of this set of interviews were highly motivated to get involved in various activities such as disability association events, or sports contests. The ones who were paralympic athletes had user experiences with highly specialized assistive products, which provided richer data related to the research questions. After completing both sets of interviews and the participant observation, the gathered data is analyzed as a whole with the help of the themes and subthemes gained and emerged from the initial analysis.

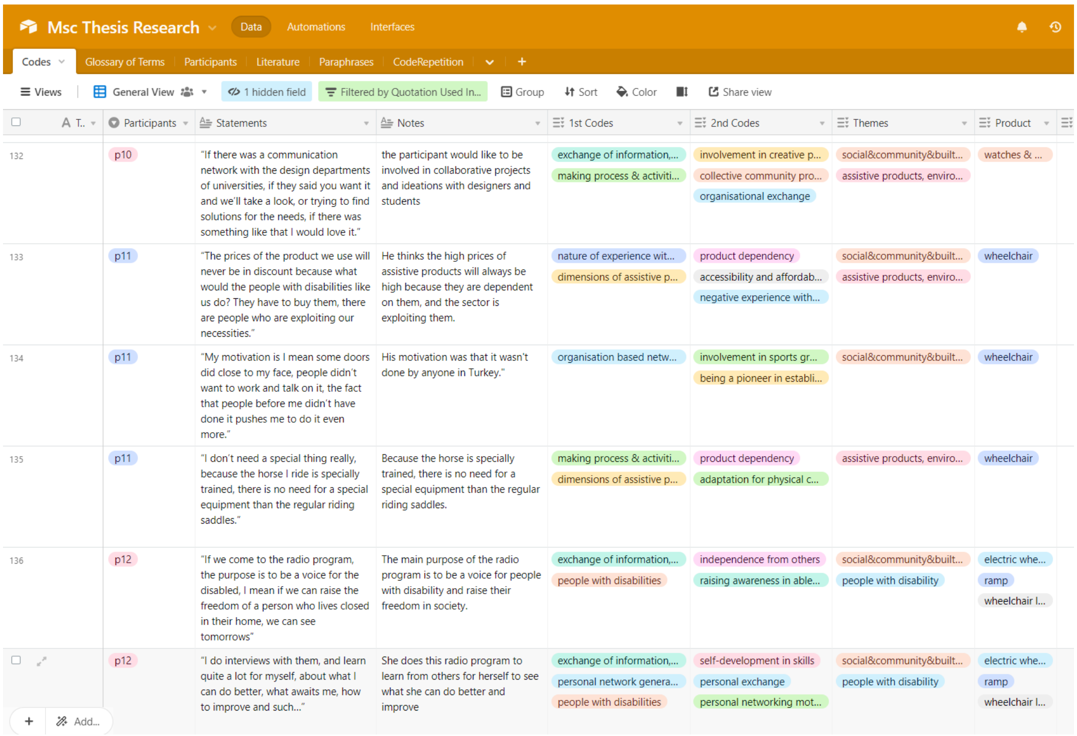
3.2.5.1 Data Transcription

Transcriptions are documents in the form of texts that are generated from the communication between the researchers and participants of a study (Widodo, 2014). In this research, I generated the transcriptions of the interview data gathered from all 16 participants by hand in the form of verbatim transcription. Although software which can generate text from audio is commonly available, the fact that several participants had speech impediments necessitated manual transcription. An advantage of personally transcribing was the opportunity to revisit the conversations, sometimes leading to understanding some sentences that I couldn’t during the interview because of either speech impediments or connectivity problems.

3.2.5.2 Content Analysis

Content analysis is “the study of the content with reference to the meanings, contexts and intentions contained in messages” (Prasad, 2008). According to Kvale (2007), this method works by categorizing the participant statements by their meaning into simple categories. Following these explanations, I applied the content analysis method for the study to analyze the main source of data that are the transcriptions of the interviews. Researchers can approach the analysis in an inductive manner, where the textual interview data is read in-depth to build meanings between the concepts and larger themes (Thomas, 2006). In this study, I developed the codes and later on the themes under which the codes and the sub-themes are clustered through an inductive approach.

As it can be seen in Figure 3.3, for documenting and analysis of the data I did not use any specific qualitative analysis software, and used the Airtable software for organizing the data sheet.



T..	Participants	Statements	Notes	1st Codes	2nd Codes	Themes	Product
132	p10	"If there was a communication network with the design departments of universities, if they said you want it and we'll take a look, or trying to find solutions for the needs, if there was something like that I would love it."	the participant would like to be involved in collaborative projects and ideations with designers and students	exchange of information,... making process & activiti...	involvement in creative p... collective community pro... organisational exchange	social&community&built... assistive products, enviro...	watches & ...
133	p11	"The prices of the product we use will never be in discount because what would the people with disabilities like us do? They have to buy them, there are people who are exploiting our necessities."	He thinks the high prices of assistive products will always be high because they are dependent on them, and the sector is exploiting them.	nature of experience wit... dimensions of assistive p...	product dependency accessibility and affordab... negative experience with...	social&community&built... assistive products, enviro...	wheelchair
134	p11	"My motivation is I mean some doors did close to my face, people didn't want to work and talk on it, the fact that people before me didn't have done it pushes me to do it even more."	His motivation was that it wasn't done by anyone in Turkey."	organisation based netw...	involvement in sports gr... being a pioneer in establi...	social&community&built...	wheelchair
135	p11	"I don't need a special thing really, because the horse I ride is specially trained, there is no need for a special equipment than the regular riding saddles."	Because the horse is specially trained, there is no need for a special equipment than the regular riding saddles.	making process & activiti... dimensions of assistive p...	product dependency adaptation for physical c...	assistive products, enviro...	wheelchair
136	p12	"If we come to the radio program, the purpose is to be a voice for the disabled, I mean if we can raise the freedom of a person who lives closed in their home, we can see tomorrows"	The main purpose of the radio program is to be a voice for people with disability and raise their freedom in society.	exchange of information,... people with disabilities	independence from others raising awareness in able...	social&community&built... people with disability	electric whe... ramp wheelchair l...
☐	p12	"I do interviews with them, and learn quite a lot for myself, about what I can do better, what awaits me, how to improve and such..."	She does this radio program to learn from others for herself to see what she can do better and improve	exchange of information,... personal network genera... people with disabilities	self-development in skills personal exchange personal networking mot...	social&community&built... people with disability	electric whe... ramp wheelchair l...

Figure 3.3. The Airtable sheet for data analysis.

According to Merriam and Tisdell (2015), coding is the act of creating shortcuts to certain parts of the research data for easier access to that specific part later in the process. During the analysis process of the study, there have been more than 550 participant statements that were related to the research interests. These statements were in Turkish, which I translated to English manually, and transferred to the data sheet. The statements that emerged from the first set of interviews were analyzed for initial coding, which helped me categorize the rest of the statements from the second set of interviews. After the initial coding of the whole data was complete, the codes were clustered in regard to their relationship with each other (see Figure 3.4), forming the 1st codes (sub-themes) and the main themes. Then the statements were analyzed for the second time to form the more specific 2nd codes (under sub-themes).

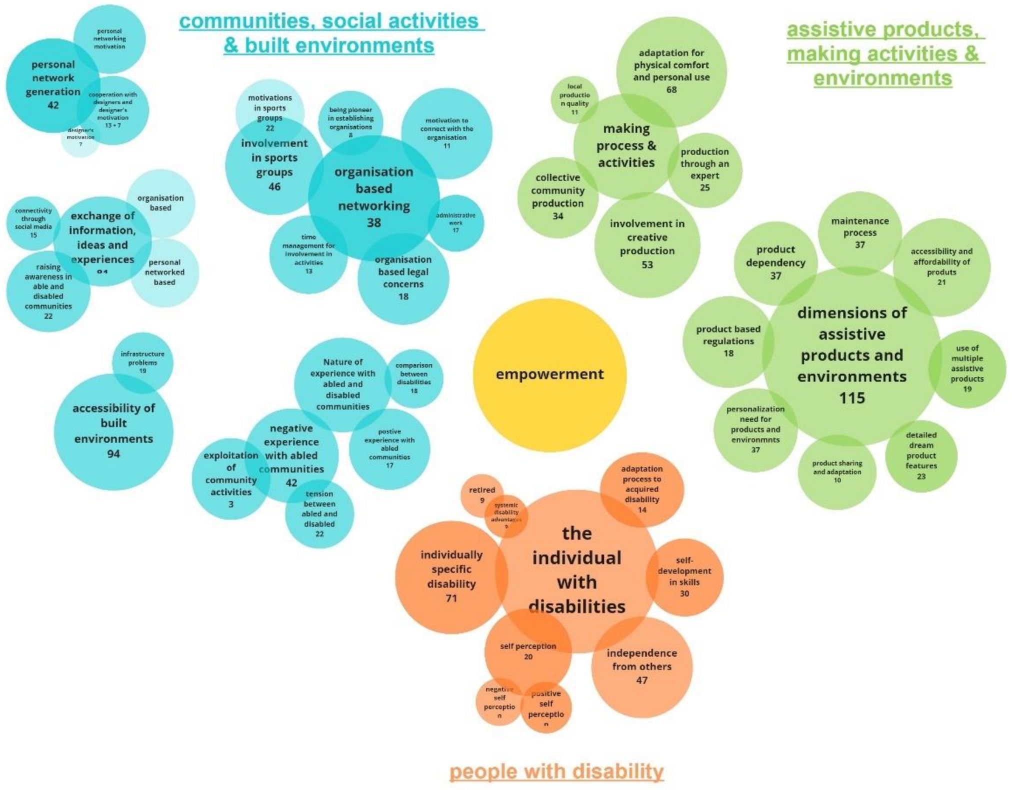
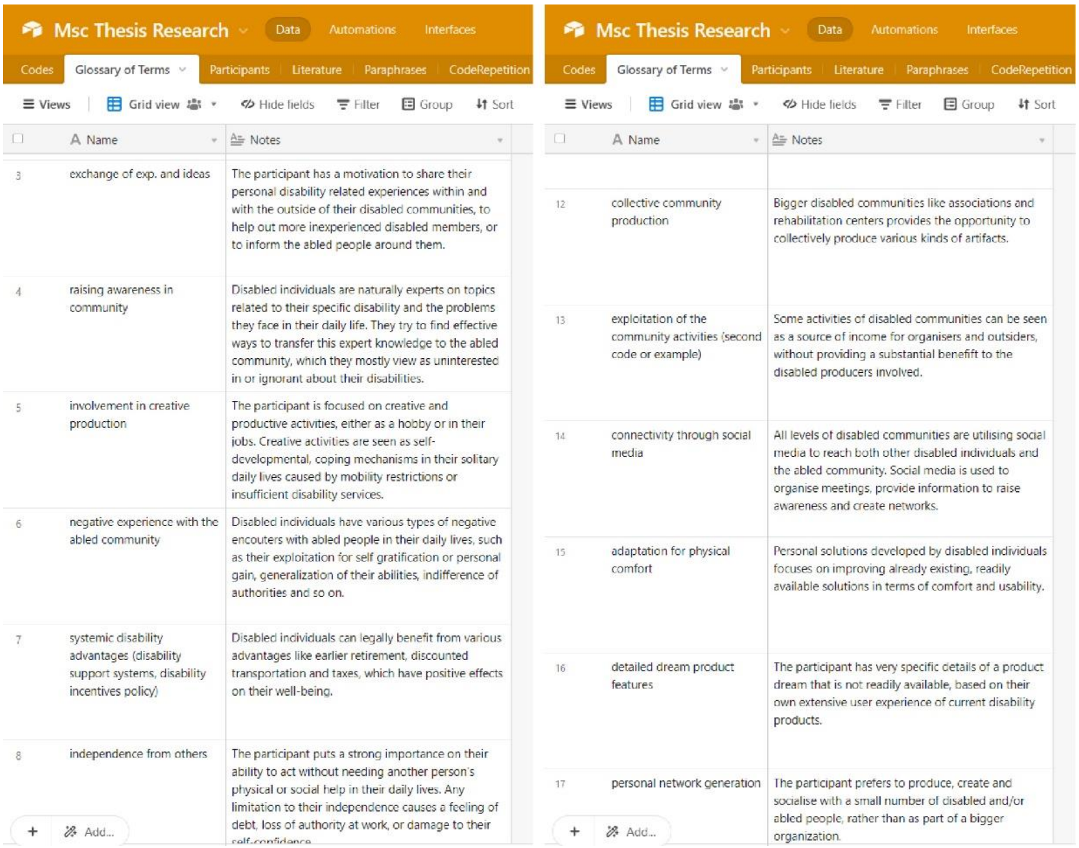


Figure 3.4. Clustering of the codes and the main themes.

Also, during the coding process, to track the meanings of each code, a glossary of terms is created to have their definitions for consistency and clarity (see Figure 3.5). As the result of the analysis, the main themes of *Communities, Social Activities & Built Environments*; *Assistive Products, Making Activities & Environments*; and *People with Disabilities*; and under them eight sub-themes were obtained (see Appendix F).



	Name	Notes
3	exchange of exp. and ideas	The participant has a motivation to share their personal disability related experiences within and with the outside of their disabled communities, to help out more inexperienced disabled members, or to inform the abled people around them.
4	raising awareness in community	Disabled individuals are naturally experts on topics related to their specific disability and the problems they face in their daily life. They try to find effective ways to transfer this expert knowledge to the abled community, which they mostly view as uninterested in or ignorant about their disabilities.
5	involvement in creative production	The participant is focused on creative and productive activities, either as a hobby or in their jobs. Creative activities are seen as self-developmental, coping mechanisms in their solitary daily lives caused by mobility restrictions or insufficient disability services.
6	negative experience with the abled community	Disabled individuals have various types of negative encouters with abled people in their daily lives, such as their exploitation for self gratification or personal gain, generalization of their abilities, indifference of authorities and so on.
7	systemic disability advantages (disability support systems, disability incentives policy)	Disabled individuals can legally benefit from various advantages like earlier retirement, discounted transportation and taxes, which have positive effects on their well-being.
8	independence from others	The participant puts a strong importance on their ability to act without needing another person's physical or social help in their daily lives. Any limitation to their independence causes a feeling of debt, loss of authority at work, or damage to their self-confidence

	Name	Notes
12	collective community production	Bigger disabled communities like associations and rehabilitation centers provides the opportunity to collectively produce various kinds of artifacts.
13	exploitation of the community activities (second code or example)	Some activities of disabled communities can be seen as a source of income for organisers and outsiders, without providing a substantial benefift to the disabled producers involved.
14	connectivity through social media	All levels of disabled communities are utilising social media to reach both other disabled individuals and the abled community. Social media is used to organise meetings, provide information to raise awareness and create networks.
15	adaptation for physical comfort	Personal solutions developed by disabled individuals focuses on improving already existing, readily available solutions in terms of comfort and usability.
16	detailed dream product features	The participant has very specific details of a product dream that is not readily available, based on their own extensive user experience of current disability products.
17	personal network generation	The participant prefers to produce, create and socialise with a small number of disabled and/or abled people, rather than as part of a bigger organization.

Figure 3.5. Glossary of terms definitions of several codes.

3.3 The Credibility of the Study

The credibility of a study determines if the findings of the research are truthfully interpreted from the data of the participants (Korstjens & Moser, 2018). To increase that credibility, Korstjens & Moser, (2018) offer strategies that can be followed, such as prolonged engagement and triangulation, which means using different sources of data. In this study, I increased the engagement of the participants by initiating the interviews with familiarizing questions that were not directly related to the research focus but was crucial to building up trust and allowing the truthful exchange of information. Additionally, as a triangulation strategy, I included various participants with physical disabilities, users of assistive devices, and members of their close circle. This variation allowed for observing different perspectives from the disabled community. Lastly, conducting the participant observation in addition to semi-structured interviews was aimed to further increase the participants' engagement and triangulate the data collection method.

3.4 Considerations on Ethics and Consent

Before starting the field research, I acquired the ethics approval of the Applied Ethics Research Center of Middle East Technical University (METU UEAM) (see Appendix E). Additionally, during the recruitment process of the study and before the interview, I sent the participants a consent form (see Appendix C). After the interviews began, I asked for the participants’ verbal consent to start the audio or the video recording. During the participant observation session, I got written approval from the principal before recording any audio or taking any photographs. While attending the classes, I also took verbal consent from the class teachers. I had additional informal conversations with the students and the teachers, but no audio or video recordings were taken of those interactions, they were only included on the field notes after the observation. The participants willingly shared photographs of their assistive products and adaptations, and gave consent to use product-related visuals on their online platforms.

The consent form that the participants signed included that the names of the participants would be anonymized, so the participants were given a number from 1 to 16. The disability associations and communities that were mentioned in the participant statements were also anonymized, such as “the association” or the “the disability community.” This was done to prevent some of the participants with recognizable roles in associations from being figured out by other stakeholders.

3.5 Summary

This chapter explains the research stages that include the sampling methods, recruitment strategies, the data collection methods, the data analysis, and the issues of credibility and ethics. In the study, I took on a qualitative and exploratory research approach, in which the data was collected through semi-structured interviews with 13 participants with different disabilities and participant observation in an inclusive high school that included three additional interviews. The field research data was audio and video recorded and was later manually transcribed verbatim. All textual transcription data was analyzed and related participant statements were organized under an Airtable sheet. The statement data were subjected to content analysis, which resulted in several main themes and sub-themes. The ethics considerations in study approval, participant consent, and anoynymity were important while planning the field research.

CHAPTER 4

FINDINGS

This chapter explains the findings of the field research that was conducted with various people with disabilities. After the process of thematic coding, the findings of the field research data is categorized under three distinct themes. The themes that will be explored are *People With Disabilities*; *Communities, Social Activities & Built Environments*; and *Assistive Products, Making Activities & Environments*. The *People With Disabilities* theme investigates the individuals with their specific disabilities, their independence from others, their own self-perceptions, and how they develop their skills and knowledge. The *Communities, Social Activities & Built Environments* theme presents the data on the social activities of people with disabilities, networks that they are involved in, their experiences, and the accessibility of their built environments. Lastly, the *Assistive Products, Making Activities & Environments* theme focuses on the dimensions of the assistive products the participants use, and their involvement in the production, maintenance, and adaptation of these products.

The findings of the analysis are explained under the sub-themes that cover numerous disability-related topics (see Fig. 4.1). At the end of each of the three main themes, their relevance to empowerment and design considerations are evaluated separately.

People with Disabilities

- Individually Specific Disability
- Independence From Others
- Self-Perception
- Self-Development in Skills
- Adaptation Process to Acquired Disability
- Systemic Disability Advantages

Communities, Social Activities & Built Environments

- Personal Network Generation
  - Personal Networking Motivation
  - Coop. with Designers & Designer's Motivation
- Organization-Based Networking
  - Motivation to Connect with the Organization
  - Involvement in Sports Groups
  - Being Pioneer in Establishing Organizations
  - Time Management for Involvement in Activities
  - Administrative Work
  - Disability-Based Legal Issues
- Exchange of Information, Ideas & Experiences
  - Raising Awareness in Abled and Disabled Communities
  - Connectivity Through Social Media
- Nature of Exp. with Abled&Disabled Community
  - Positive Experiences with Abled Communities
  - Negative Experiences with Abled Communities
  - Comparison Between Disabilities
- Accessibility of Built Environments

Assistive Products, Making Activities & Environments

- Dimensions of Assist.Products and Environments
  - Personalization Need for Products&Environments
  - Use of Multiple Assistive Products
  - Product Sharing and Adaptation
  - Accessibility and Affordability of Products
  - Product Dependency
  - Maintenance Process
  - Detailed Dream Product Features
  - Product Based Regulations
- Making Process & Activities
  - Involvement in Creative Production
  - Collective Community Production
  - Adaptation for Physical Comfort & Personal Use
  - Production Through an Expert
  - Local Production Quality

Figure 4.1. List of themes and sub-themes.

4.1 People With Disabilities

This theme investigates the personal sphere of people with disabilities. This sphere includes the individually specific disabilities that are unique for each person, the motivation for being independent from other people, the self-perceptions of people with disabilities, how they develop their skills, the adaptation processes when a disability is acquired, and the systemic advantages that they are entitled to. Figure 4.2 illustrates the sub-themes under the main theme of *People with Disabilities*.

Figure 4.2. The sub-themes of People with Disabilities.

4.1.1 Individually Specific Disability

The participants repeatedly emphasized the uniqueness of each individual’s disability. The types and levels of disabilities can greatly vary from person to person, leading to problems when faced with the generalization of a disability group. *Participant 1* explains his experience with the perception of crutch users:

> *"I said her disability is different from mine. Because everyone categorizes the disabled like this, I mean, if you are able to do this specific thing, then the others can too. It is a huge problem, they think and act for you without asking, for good intentions but it makes our lives harder."*

The same individuality also exists for people with cerebral palsy, even to a greater extent. As *Participant 3* points out, there is a wide range of effects that CP can have on a person:

> *"CP is very much individual, unique to a person... my need is not a problem for many, their needs are not for me, but I always ask this... what stops us from participating in life? How can we overcome that barrier?"*

Continuing his explanation, *Participant 3* also emphasizes the importance of the assistive solutions being in the same level of uniqueness as the person's disability:

> *"I don't use a wheelchair inside the house, I prefer to crawl on the inside, I can go anywhere without a problem, that's also a solution. The important thing is to develop individual-specific, or even disability-specific solutions. What is the problem, the need, and what can be done? If we ask these questions, I believe we can develop solutions for every disabled person."*

Furthermore, the need for tailoring the assistive products to the individual specifics of the person's disability increases the involvement level of the user in the production and/or adaptation processes. *Participant 7* explains the effect of individually specific disabilities on paralympic sports products:

> *"(Talking about whether the sports federation provided the archery accessories) No, we made them, because everyone's disability structure is different. We need to find in which position we are more comfortable shooting by trying out ourselves."*

Although this situation makes the users with disabilities more active in the production, they still require expert knowledge and production-related skills from outside sources. As it will be explained under the heading of *Production Through* *an Expert* (see Section 4.3.2.4), different teams of paralympic archery that have members with a differing set of disabilities resulted in the specialization of expert producers who focus on a certain disability type and level, and generate a network of customers in that disability group.

The uniqueness of disabilities that changes from person to person is also stated to affect the person’s placement in an organizational network. A special education teacher (*Participant 15*) who works at the inclusive high school in which the user observation took place explains how the inclusive education system works in their classes:

> *“The content of the class is shaped individually for each student's level of abilities and skills. We roughly evaluate the student’s level of abilities and place them on a spectrum. Then we develop course plans to improve each student's abilities.”*

4.1.2 Independence From Others

The strongest motivation in many decisions, such as participating in community activities or adapting assistive products is reported as having personal independence from other people. *Participant 5* stresses his need to be independent in the actions he has to make during his work:

> *“You can say that you can ask for help from your co-worker. No, I don't want such a thing. I mean, constantly asking for help, ten times a day from someone, even a really close friend won't do. If I ask a nearby student to write the names and surnames for me, then my authority is shaken.”*

It can be argued that being independent of others is seen as an integral part of a person with a disability’s self-perception. *Participant 13* talks about the positive effect of being able to walk without help had on his son’s self-perception (See Figure 4.3):

> *"(Talking with his son's walker) I can draw that if you like, it was a really nice thing; my son used it a lot. He could walk around the corridors on his own, and the kid got self-confidence with it."*

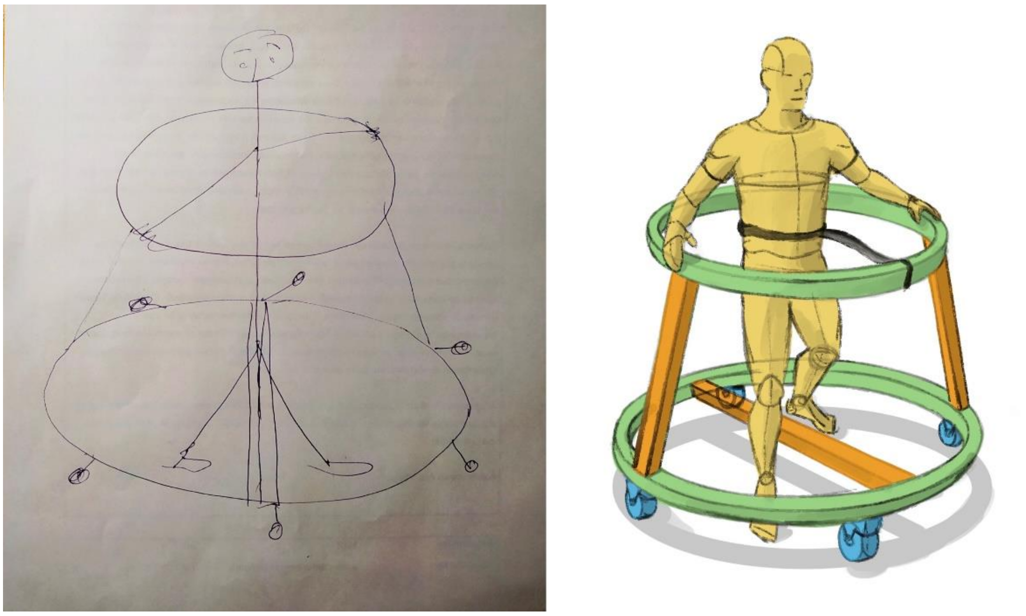


Figure 4.3. The participant's quick drawing (left), and the re-creation of the design sketch (right).

Similarly, *Participant 1* explains his feelings of debt to his friends he had before acquiring his accessible automobile:

> *"I also don't like saying other people take me there, pick me up from there; I would get uncomfortable even if they offered it. I wanted my own freedom; in that sense, it's (the accessible automobile) good and I can go anywhere I like."*

In addition, the assistive products that people with disabilities have and their usability also affect the people's independence from others during the product's use, as *Participant 7* states:

> *"Because those wheelchairs' armrests were too high, my arm for example, couldn't reach over to the wheels, I couldn't drive it by myself, I was getting lost in it…"*

Moreover, the accessibility of public products and environments can limit the independence of a person with disabilities. *Participant 2* states the reason for people in social services getting distanced from the outside community:

> *"It's easier on Saray (social services) than the outside; you have to go outside and that isn't easy to make yourself accepted. Because I use public transport, I have to call on others' help to get on and off the bus..."*

Similarly, *Participant 7* points to her dissatisfaction with the city's accessibility solutions:

> *"For example, there are ramps on the entrances of Marmaray, one of which is very steep, when passing through my wheelchair slides. Most of the time, I have to get help from someone nearby to prevent the sliding."*

Lastly, some participants with severe disabilities that limit their bodily functions need the help of a family member to take care of their daily needs. This dependence is not perceived as negatively as the abovementioned dependencies on other people. *Participant 12* states that although she sees her electric wheelchair as a freeing tool, she still takes help from her father in their home:

> *"(Talking about whether she uses a wheelchair inside the house) My father takes care of me, on his back. He helped and carried me on his back for 28 years…"*

4.1.3 Self-Perception

Through the statements of participants, it can be argued that various factors affect how people with disabilities perceive themselves. *Participant 1* explained the negative perceptions involving the people with disabilities as a doing of the disabled community:

> *“The thing that the disabled people are always feeling as the victims, pitiful, and in need of help… The world does this to us anyway, but I find it odd when the disabled person accepts this.”*

Similarly, disability-related products can also have negative connotations, resulting in problems adopting the product. *Participant 12* recalls the reason for starting to use her wheelchair late:

> *“I never accepted being disabled and had many regrets because of this. I didn’t use a wheelchair until I was 12 years old because it felt like if I did, people would pity me.”*

This situation can also be seen in the case of *Participant 10*, where her father refuses to use the assistive products that he needs because of his negative perceptions:

> *“They refuse to use some of the products, see them as being old. I wanted to get him used to it earlier, like hearing aids or canes, but he still doesn’t want to use them.”*

Other than negative self-perceptions, the participants perceive themselves more positively and prouder when involved in disability community activities. *Participant 2* emphasizes his satisfaction with his job, which involves children with disabilities:

> *“When the group that I work with sees me, it changes their perspective in life. They become more lively, want to be like me, that's what I observed, I really enjoy doing my job.”*

Similarly, *Participant 3* connects his self-perception with the benefits he provided to his disability association:

> *“(Talking about winning the wheelchair idea competition) I felt like a pop star these days, we spent great days together... TSC association gave great*

> *services, education, and therapy to many kids with CP; if I had any kind of contribution in that, it would make me happy."*

In both cases, the participants reported a positive self-perception when they saw themselves as the *helper* instead of being the *helped* one.

4.1.4 Self-Development in Skills

People with disabilities seek to develop their physical and social skills. They try to accomplish this self-development through community, making and physical activities. *Participant 4* explains that the skill development came from the making activities they took part in the social services:

> *"Not just talking about Saray (social services), all social services or other state institutes, spending time in them was tough, we always aimed for producing something, doing something to relax...."*

The participants also reported the need to develop themselves physically to mitigate the negative effects caused by the lack of body movement. *Participant 7* states that her history with sports goes before her paralympic career:

> *"Sports were already in every part of my life; I was going to my swimming, to the gym, we have to do this to sustain the overall body. Because disability doesn't like laziness, it is very open to body deformation. That's why I have always been doing sports."*

In addition to actively doing sports activities, some participants have to do physical rehabilitation to sustain their skills. *Participant 13* talks about the activities his son needs to make at home:

> *"He can climb to get somewhere, but we couldn't get him to walk. He needs to make lots of physical rehabilitation moves. When we decrease them it becomes worse... We also installed parallel bars at home to practice."*

Moreover, self-development of knowledge and social skills is also apparent. *Participant 12* says that self-development is an additional motivation in doing her radio program:

> *"(Talking on the next episode of the radio program) How should the disabled eat, why we get tired easily, we will talk about those. My target is disabled, and I will get a make-up artist, the practical ways for the disabled make-up… I will get an engineer if there are assistive software and stuff. I want to research those; the radio program also provides me with this research."*

4.1.5 Adaptation Process to Acquired Disability

In several cases, the participants did not have their disability from birth, but they acquired it at some point in their life. It is also observed that the adaptation process of a recently acquired disability can affect their community participation and how the assistive products are used. *Participant 6* recalls her first experience of being a colostomy bag user after a medical operation:

> *"After the surgery, I started to use it (colostomy bag) ... Yes, there is a community, but I found them late... A special nurse came in the hospital and put it on me."*

Furthermore, suddenly acquiring a disability can also negatively affect a person's self-development. *Participant 7* explains the combination of reasons for not being able to continue her education:

> *"I became disabled after an injury I had at 11 years old. I couldn't continue school because of that and the architectural problems of that time."*

On the other hand, acquiring a disability can also gradually occur over time. *Participant 10* explains how her father slowly acquired his impairments:

> *"These people get various deteriorations because of aging; they are not sick. We spent sad years… After an age, he started to do word puzzles and activities like that, and one morning, he couldn't see the puzzle he put on the table yesterday. It was extremely frustrating for him."*

It can be argued that the initial experiences of an acquired disability can be quite stressful for the individual, causing uncertainty about what activities to participate in, and which assistive products to use.

4.1.6 Systemic Disability Advantages

People with disabilities are legally entitled to various advantages. These advantages change considerably depending on the disability type and level, mostly involving working conditions and monetary support like tax discounts. *Participant 1* explains how he can afford to do voluntary work in social media:

> *"I'm retired, was able to do that early because of the disability, and have an income."*

Retiring earlier allows people with disabilities to have more free time for other activities, increasing the potential for participating in making activities. *Participant 4* talks about the artworks he was able to make after retirement:

> *"I'm a retired government employee. I made oil paintings. I live in İzmir, interested in arts, currently doing voiceover works."*

In addition to providing ample free time to people with disabilities, there are systemic advantages regarding assistive products and product adaptations as well. *Participant 1* talks about the monetary advantages he was entitled to while acquiring an accessible automobile:

> *"There is also an ÖTV (special consumption tax) discount for automobile purchases by the disabled. They also allow you to renew that every five years; it is that time, so I plan to sell the old one and get a new car."*

Although the participants report positive experiences with these advantages, there could also be negative indirect effects. *Participant 7* explains that when she reached the early retirement age for the disabled, she had problems finding employment:

> *"(Talking about after retirement) I looked for work but couldn't find any… they employ us because of the disability law. They were saying you already retired, let the others get retired too, and rejected me."*

Lastly, *Participant 13* explains the need for additional systemic advantages for the close proximity of people with disabilities.

> *"If both parents are working, one has to quit their job. I also said this to the ministry of family and social policies; we need to get these people (family members of the disabled) in social security."*

4.1.7 Theme Relevance to Empowerment and Design Considerations

The abovementioned concepts under the theme of *People with Disabilities* can be evaluated in terms of their relevance to the empowerment of people with disabilities, by utilizing Zimmerman's Empowerment Theory (2000). The concepts found in the field research will be related to the three elements that the Empowerment Theory defines:

- being able to control and access resources,
- participating with others,
- having critical awareness of the socio-political environment.

Participants acknowledging the differences between every person with a disability and assessing the stronger and weaker sides of their own *individually specific disability* can be linked to the empowerment element of having critical awareness of the socio-political environment. By communicating their unique set of abilities and limitations, people with disabilities can improve the empowering effects of the assistive products that are designed for them. As a design consideration, *Participant 3* gives an insight into his specific needs that wouldn’t be satisfied with a general-purpose solution, hinting at the need for individually specific design solutions:

> *“Me, for example, I can only use one hand; I have difficulties getting dressed. Clothing, shoes that I can get in with one hand would be very useful.”*

Awareness of their specific needs and communicating them with others improves the possibility of empowerment. Moreover, the participants’ main goal of having their independence from other people is observed to be reached when they could have access to and control over resources, such as suitable assistive products that work as intended and accessible environments. The strongest cases of empowerment were the ones where the participant already had access to the assistive products, and increased their independence from others by *increasing their control over the product through adaptations*. Furthermore, it can be argued that there is a two-way relationship between people with disabilities, including *independence from others* and their *product dependency*. The more individually specific and specialized the assistive product gets through adaptations and added functions, the more empowerment the user gains in terms of being independent. At the same time, however, the user’s dependence on that specialized product to accomplish their daily tasks and functions also increases (see Figure 4.4).

Figure 4.4. The proportional relationship between the concepts of independence from others and product dependency.

Moreover, positive self-perception of the people with disabilities was closely linked to how much of a help they saw themselves to others. Thus, how people with disabilities achieve positive self-perception is directly related to the empowerment element of participating with others. It can be argued that this motivation of being the *helper* for other members of disabled communities can be utilized to improve people with disabilities' *participation in collective making activities*. Participants' tendency to involve in self-development activities can also support this argument, as participating in collective maker activities would both improve their making skills, and result in artifacts that would help other people with disabilities.

There could also be a design opportunity in a currently disempowering stage of the life of a person with disabilities. As discussed under the heading of *Adaptation Process to Acquired Disability* (see Section 4.1.5), When a person acquires any form of a disability during their life, they are forced to adapt to a completely new physical and social context of living. It can be argued that the statements of stress and uncertainty from the participants who had an acquired disability show the disempowering effect of not having an awareness of the social context. Those participants also stated that they joined associations related to their newly acquired disabilities, which can be interpreted as an empowerment strategy for participating with others. Thus, providing opportunities for better access to disability communities and collective activities would empower people with acquired disabilities to gain awareness of their new social contexts.

Lastly, as a similar approach to the concept of Product-based Regulations, systemic disability advantages that people with disabilities are entitled to are also linked with the empowerment element of being aware of the socio-political environment. The participants who are knowledgeable about their financial and social advantages in the law utilized these systems to acquire assistive products easier, have financial support and have more time for self-development.

4.2 Communities, Social Activities & Built Environments

This theme investigates the social sphere of people with disabilities' activities. This sphere includes the personal networks that they generate within and outside of disabled communities, their motivations for networking, wider organization-based networks that they are involved in, how they exchange their knowledge and experiences in these networks, positive and negative natures of their experiences, and accessibility of the built environments in which they live. Figure 4.5 illustrates the sub-themes under the main theme of Communities, Social Activities & Built Environments.

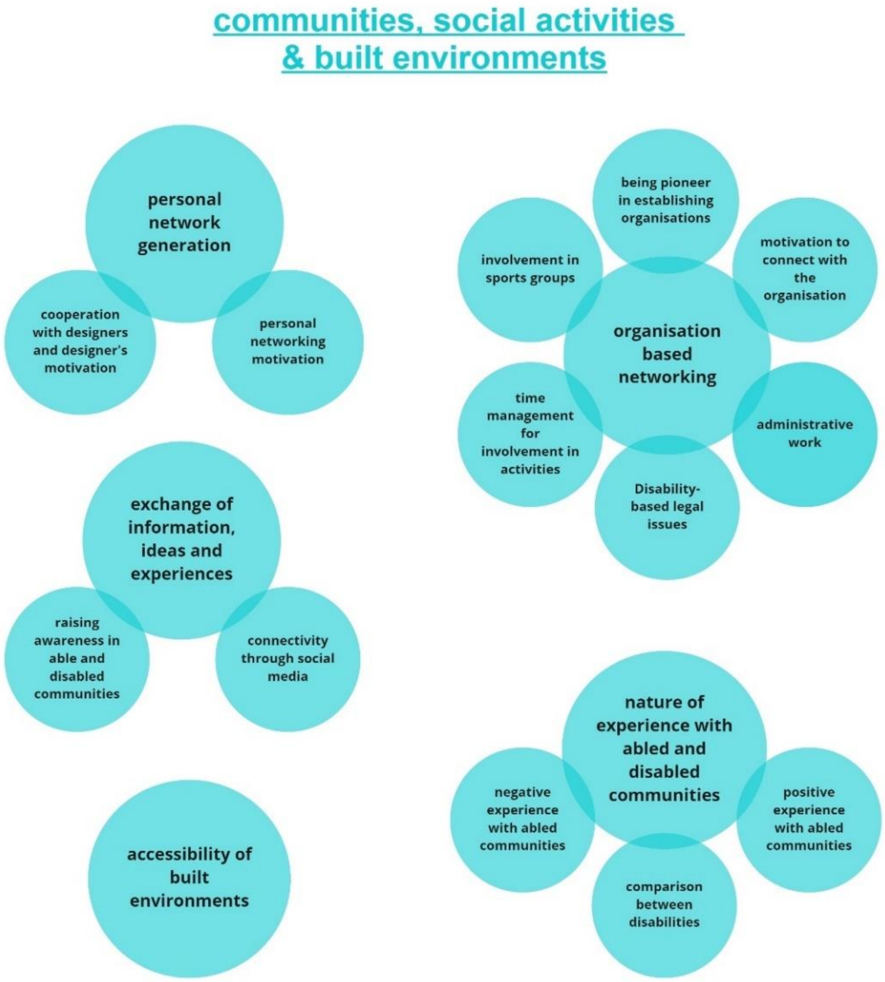


Figure 4.5. The sub-themes of Social & Community & Built Environment.

4.2.1 Personal Network Generation

The most commonly participated form of community is the relatively small personal networks which the participants organically generate in their daily lives. They build their networks in varying contexts and for varying purposes. For example, when talking about his designer friends whom he wants to collaborate with, *Participant 1* explains that they connected with each other through a non-design or a non-disability-related context:

> *“He was a friend from the green party, the other friend I met while making a news story for the newspaper. There was an environmental meeting at Kaz mountains; that’s how we met, friends from ecology activism.”*

While this particular network was generated from an event unrelated to disability, some participants developed their network specifically through their shared disabilities, as *Participant 3* defines their disability awareness group:

> *“We have this group since 2018, Cerebral Palsy Turkey Awareness Group, composed of four people, one journalist, one psychologist, one physiotherapist; the thing all four of us have in common is CP.”*

Another form that people with disabilities build their personal networks through their need to produce, maintain and adapt their assistive products. Participant 7 remarks on her process in building her network for making special accessories for paralympic archery:

> *“He was in a medical close to my previous home, and it took a lot of time to find him. No other medicals wanted to work on it because it required lots of detail, I went to them, and they agreed… That’s how we started working, became friends, still connected.”*

The reason for the variation in the participants’ approaches when generating their personal networks can be explained by the differing motivations of people with disabilities for building the network, and the motivations of others in becoming a part of that network.

4.2.1.1 Personal Networking Motivation

The participants are observed to have multiple personal networks that they employ for different purposes. The people in their networks can provide them with a particular skillset, or an exchange of experiences related to their disabilities and assistive products. To illustrate, when communicating with a team of university students during a collaborative project of developing a solar-powered wheelchair prototype (see Section 4.2.1.2 for further details), *Participant 3* required the visual skills of a graphic designer and utilized his personal network:

> *"I also had this idea in the second phase... I had a graphic designer friend draw an idea and sent it to them (the students) so that they can understand it better; solar panels should be like this, smaller and behind the wheelchair."*

Apart from needing a skill that they don't personally have, the participants are also interested in generating their networks to learn from more experienced disabled people, such as *Participant 12*, who is doing a radio program about disability:

> *"I do interviews with them and learn quite a lot for myself, about what I can do better, what awaits me, how to improve and such…"*

Personal networks are also being utilized to improve other networks of a person with disability, exemplified in the statement of *Participant 4* about the knowledge of how and where to do their wheelchair maintenance:

> *"Of course, I have other electric wheelchair users in the neighborhood. We ask each other where we can do maintenance, where you bought this chair, how much the battery is and so on... Naturally, we ask and help each other."*

Whatever the motivation for personal networking is, the process of generating the network seems to be bottom-up, initiated by the efforts of the person with disability.

4.2.1.2 Cooperation with Designers and Designer's Motivation

Sometimes, a personal network is generated between a person with disability and designers. In other cases, the need and the motivation for the non-existing cooperation with the designers are apparent. For example, *Participant 10* explains the frustration she experiences caused by the lack of communication:

> *"For the designers, it could be really easy to do this, our wants are simple, but we can't reach the people who can do it."*

Moreover, the motivation to initiate this communication can be seen on both sides. From the disability side *Participant 12* states that she is hopeful about cooperation with universities and students about these products:

> *"I'm counting on you; especially METU. I did many interviews with METU communities. I'm hopeful with you people and the things I said, for example, the wheelchair controller, software can be added to it…"*

For the designer's motivation to initiate the network with the disabled community, the example of potential collaboration in the future from the designer friends of *Participant 1* can be given:

> *"I talked about my idea to a designer friend, and he said to me: we can do this, the biggest problem of a designer is not having an idea, I mean you dream we can do the rest, that's our job. Because we don't know the problem, you give us details and nuances. We know the material and the tools."*

In addition to this local example of designers' motivations, a global example that has a real-world result can be the unique experience of *Participant 3* in an idea contest that involves realizing his winning product idea through the help of international engineering students from the USA (see Figure 4.16):

> *"Turkey Cerebral Palsy Foundation, which tried really hard to realize this idea into real life, went to many universities, but no positive answer came from Turkey, but Virginia University in the US had a team of engineering students who were interested in, who came together and realized my idea."*

The details of the interaction and exchange of information between the students and the participant will be discussed later under the headings of *Exchange of Information, Ideas, and Experiences*, and *Theme Relevance to Empowerment and Design Considerations*.

4.2.2 Organization-Based Networking

In addition to generating their own personal networks, the participants are also members of various organizations. These organizations are mainly disability-related associations, institutions, and sports groups. As it can be understood from the statement of *Participant 1*, the disability associations organize joint activities with association networks, creating a wide networking opportunity:

> *"There is the Department of Disabled in Mersin, during the Disability Week, which is on every 10-16 June, they organize a joint event including every disability groups, we participated in that (in 2021)."*

Other than voluntarily getting involved in disability-related associations, some participants grew up in social services and rehabilitation centers, involuntarily being members of a closely-knit disability community. *Participant 4* talks about the rehabilitation centers where people with disabilities created networks with non-disabled educators as well as their colleagues with disabilities.:

> *"We learned together with our teachers in the rehabilitation center. They always helped us."*

In the case of sports groups, being a member of one sports branch allowed *Participants 8* and *9* to get involved in other branches through the community network of the sports federation, *Participant 8* states:

> *"(Talking about the federation) It developed and grew; we started with table tennis, then we wanted to try swimming, then we looked and saw the branch of dancing was passive, we had an offer if we could do that."*

4.2.2.1 Motivation to Connect with the Organization

There are varying motivations for a person with disability to initiate or sustain their connection with an organization. On one end of the scale, some participants, such as *Participant 1* states his reason for joining the disability-related association is mostly utilitarian:

> *"I'm an old member of the association. The reason I joined was to be able to go to Galatasaray matches with a disabled ID."*

While some participated in their organizations for the personal benefits that being a member brings, on the other end of the scale, certain connections with organizations are highly emotional, such as the connection that *Participant 4* has developed with the social services throughout the years:

> *"I'm talking about the people close to me; we have more of a brother relationship than a nursery kid-teacher relationship."*

Combining these motivations of personal benefit and emotional connection, other members of disability associations feel indebted to their organization because of the previous help they got from them earlier in their lives. *Participant 3* explains why he is still connected to an organization that is specialized in spastic children:

> *"We have an emotional bond with Turkey Spastic Children Association. I used to take physical therapy from them when I was a kid. I follow them with many other organisations."*

As exemplified by *Participant 7*, some members of associations are actively participating in events as they see that as paying back their debt to the association:

> *"Seasonally I participated in the volunteer works of the association, and to be able to pay my loyalty debt back I volunteered a lot back then."*

4.2.2.2 Involvement in Sports Groups

Several participants had exclusively active involvement in paralympic sports branches. They initially participated in sports activities in their personal lives, and got involved with sports organizations through their networks. *Participant 7* explains the time required for the sport and how she started paralympic archery after her retirement:

> *"The muscle power is usually insufficient in us (wheelchair users), allowing muscle formation takes a lot of time; I mean, I couldn't even stay at my home. I spent two-thirds of a year in sports camps."*

Because of its time-consuming nature, getting involved in paralympic teams creates a focused network for people with disabilities during their time with sports groups in various training camps. Furthermore, as stated by the paralympic dancer *Participant 8*, the context of training camps allows for the interaction of different sports communities with each other:

> *"Let's say three athletes are in Istanbul, the rest is all at Antalya, and in every two months, we organize development camps, choreography works, and national and international competition camps."*

The constant interaction between different paralympic sports groups also renders it possible for paralympic athletes to try out other sports branches, developing their skills further in multiple ways. This is shown by the commitment of *Participants 8* and *9* to train for another sport:

> *"We are also continuing to train in paralympic archery for a couple of months, as an additional branch, our purpose there is also getting into the national team and earning the right to represent our country."*

Moreover, as *Participant 7* points out, being actively involved in sports increases the overall fitness that helps with daily tasks, resulting in increased autonomy and confidence:

> *“In many ways like transferring from the wheelchair to another spot, when the muscles are strong, you can do these things easily before all else it gives you a strong self-confidence. The belief of being able to do anything saves the person.”*

Apart from improving their sports skills and overall autonomy, training for certain competitions makes the para-athletes experienced users of specialized assistive products. *Participant 7* remarks on the effects of competition types on her products and accessories:

> *“Yes, for the W1 class paralympic archery, those accessories and modifications are obligatory to have.”*

W1 category means that the athletes have an impairment in their torso and at least three limbs (International Paralympic Committee, 2022).

The details of specialized sports products and accessories will be discussed further under the headings of the third theme, *Assistive Products, Making Activities & Environments* (see Section 4.3).

4.2.2.3 Being Pioneer in Establishing Organizations

Whether the organization is a disability-related association or a paralympic sports team, some participants took the role of a pioneer and actively worked on establishing either the organization as a whole or their specific field. Being a pioneer naturally requires more effort from the participants compared to if they were joining an existing community. *Participant 7* talks about this difference while she was preparing for the Paralympics:

> *“It’s going very intense because the year I started paralympic archery was the year of the Olympics, and because I was the first contestant from Turkey, preparation work for the Olympics was highly intense.”*

The motivations for going through such extra efforts depend on whether the context is an association or a sports team. As explained by *Participant 11*, who is a para-dressage rider preparing to be the first contestant from Turkey in the next Paralympics, the notion of being the pioneer in his country was enough of a motivation:

> *"My motivation is, I mean, some doors did close to my face, people didn't want to work and talk on it, the fact that people before me didn't have done it pushes me to do it even more."*

In the context of associations, when there is a lack of specific associations for the disability of an individual, establishing that certain organization becomes a necessity for the participant to generate their own community and to obtain visibility in society. *Participant 13* explains the time that their association has in his life:

> *"For thirty-two years, I have been in this sector. I'm the founder of SERÇEV and still the association's board president. So, I know our families well."*

In addition to being apparent on an individual level, the concept of being a pioneer can also be seen the association level. The association that focuses on children with cerebral palsy, which was founded by *Participant 13*, is also a pioneer association in the sense that they led the process of establishing the first inclusive high school in Turkey, where the students with disabilities, mostly CP, autism and paraplegia, and students with normal development are studying together (See Figure 4.6:

> *"It's the first special technical Anatolian high school in Turkey, for the disabled, we have nine special educator personnel there, healthy kids, and people with disabilities are together."*

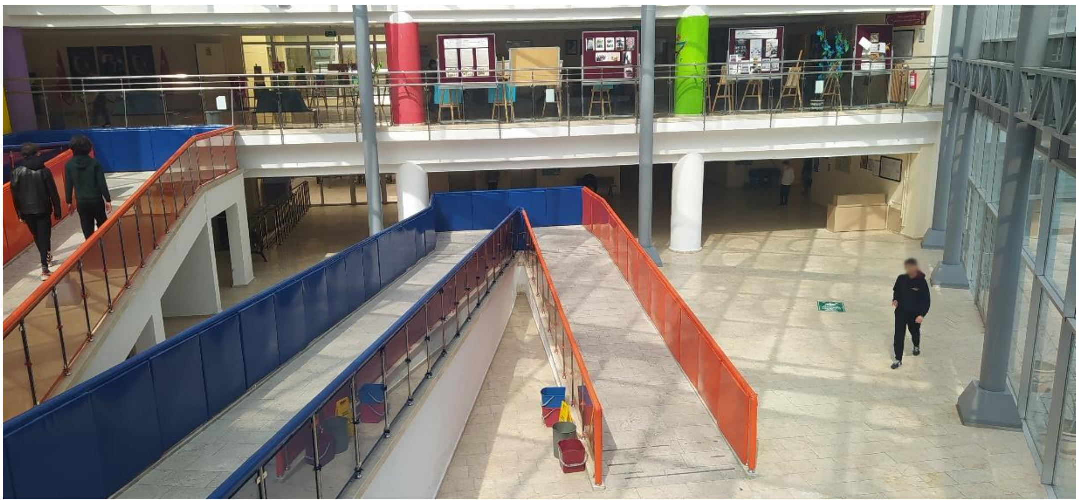


Figure 4.6. The inclusive high school built by the disability association.

The association as a pioneer in establishing other organizations also stems from the needs of the association members; in this case, most students are also members of the association.

4.2.2.4 Time Management for Involvement in Activities

People with disabilities reported having difficulties in managing their time while actively participating in organizational activities. The problem can be caused by either the activities of different communities competing for the individual's limited time or because the person is connected too closely with the organization. To exemplify the latter, *Participant 4* explains why he spends most of his time with art activities outside of the social services:

> *"You got to fill your time somehow; you spend inside 24 hours... It might not be a good thing to spend all your time in the same place, always seeing the same faces..."*

People who are members of multiple communities choose to prioritize one activity over the others, such as the case of *Participant 7,* focusing solely on sports training:

> *"I'm not currently taking active roles in the association. As I said, I started the sport after retirement. Since I started it, I stopped everything else; all are sports right now.*

In terms of making activities, they are planned as extra daily activities and duties. *Participant 14,* who is an informatics teacher in the inclusive high school, comments about how she and her students build their robot project:

> *"For the duration, we had 7-8 weeks, you have to make it (the robot) from scratch, I can say we worked day and night, we went to the home after midnight, it was our first year in the competition."*

4.2.2.5 Administrative Work

The management of disability-related organizations is observed to be undertaken by the members with disabilities. *Participant 5* recalls his own administrative experiences in disability associations:

> *"In associations, what happens is a couple of maybe 4-5 people take the initiative, and it works from there; they take the weight."*

Motivated individuals who take part in establishing organizations and communities are also actively involved in administrative work, even in more than one organization at the same time, as shown by *Participant 13*:

> *"I'm at the association, in the sports club, in the foundation, we are also in the city council, in the school… we also have Barrier-free Cerebral Palsi sports club, we founded a para-volleyball team."*

4.2.2.6 Disability-Based Legal Issues

There are many general regulations and laws regarding the associations and disabilities, which causes legal concerns in some participants about their own disabilities, or while participating in disability associations. *Participant 1* explains the legal reasons behind his leave from the disability association:

> *"My friends told me you are seen as the president; if there were misconduct in the activities, you would take the blame. I mean, you can't just say I didn't know when you are the president, so I wasn't comfortable and left that association."*

Other than legal responsibilities in associations, some participants complain about the laws and procedures in place for their specific disabilities. *Participant 6* comments about the invisibility and the associated legal issues of being a colostomy bag user:

> *"It isn't known as a disability; it is never talked about, ministry of health doesn't care about it... this disability is not known and invisible to the outside, it's a big problem if you think about it."*

4.2.3 Exchange of Information, Ideas, and Experiences

Both the personal networks generated by people with disabilities and the organizations that they are members of are founded on the premise of exchanging information, ideas, or experiences between the participating parties. For giving an example of exchange on a personal level, *Participant 3* recalls his experience of giving user feedback to the engineering students after he received a prototype wheelchair of his product idea (see Figure 4.7):

> *"The vehicle came to us, and I used it for a while, I also gave them some ideas on how to improve it, because it was a really big thing, getting inside places was a problem, I advised them on how to minimalize it."*

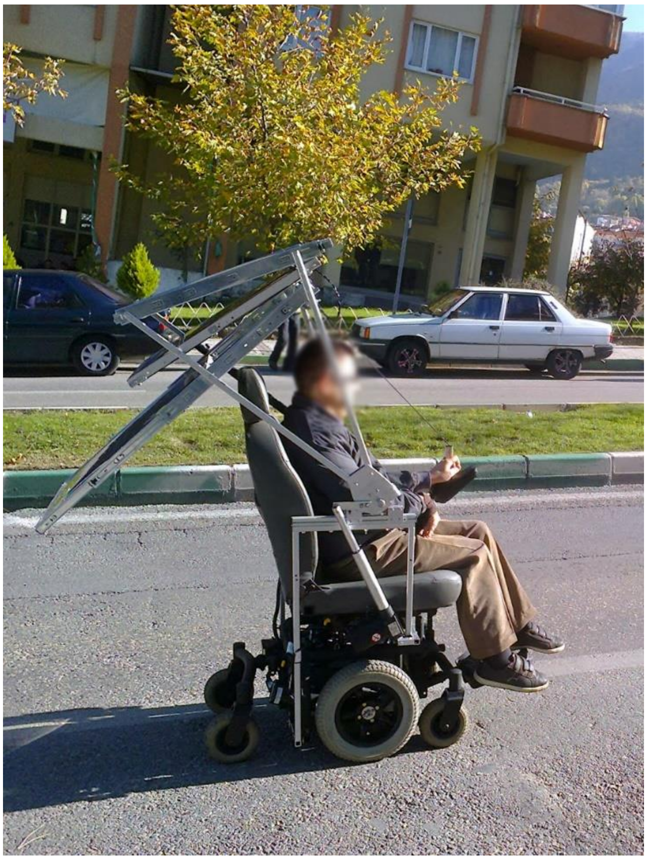


Figure 4.7. Participant 3 using his prototype wheelchair with solar panels.

The personal exchanges of product-related experiences are not limited to communicating with people who make design decisions on assistive products. *Participant 7* gives the example of an instance where more experienced users of assistive products transfer their acquired knowledge to novice users, in this case, how to use the bow, maintain or adapt it while using:

> *"We have a little friend who is growing up, 14 years old. When necessary we give him information about the bow or any other part, and we share our experiences with him."*

On the other hand, the organizational exchange of information can occur between organizations and disabled communities. *Participant 5* works as a psychological consultant in a high school, and he explains how they organize experience exchange events with both the disabled and abled communities:

> *"Disabled people, their family members, we give training courses to them. Other than them, high school students, university students, primary schools... what we call experience exchange, we toured these schools and shared our experiences."*

These types of experience exchanges aim to improve the daily lives of people with disabilities by sharing helpful strategies developed by experienced members of the disabled community and increasing the disability knowledge and awareness of the abled communities. *Participant 11* emphasizes the importance of active participation of the disabled community in exchanging information with the abled communities:

> *"The people with disabilities need to go out and be in the social environment much more. When they are not involved in the society, it creates ignorance about their problems, and that creates a lack of awareness."*

Thus, it can be argued that information exchange in communities is an effective way to raise overall disability awareness, which is discussed in the next section.

4.2.3.1 Raising Awareness in Abled and Disabled Communities

The main motivation for exchanging information, ideas, and experiences is raising the disability knowledge and awareness levels of both abled and disabled communities. *Participant 5* points out his aims for the future versions of experience exchange sessions which would aim to raise the awareness of the medical community:

> *"Especially, I emphasize making big experience exchange events with medical schools because people with CP and the disabled live most of their time inside the hospitals. That's why increasing the doctors' experience, and awareness in this subject would really help the patients."*

Raising awareness of the general population rather than a specific target group like medical workers is also an apparent motivation. *Participant 1* talks about his plans for a podcast idea that will explain important questions related to disability:

> *"There is that podcast idea of mine that I want to do individually because I have a disability... Who are the disabled? What does it mean? Impaired, disabled, cripple, which one is true or wrong?"*

Similarly, *Participant 12* has been hosting a radio program that invites disabled people to share their experiences with the general public:

> *"If we come to the radio program, the purpose is to be a voice for the disabled; I mean, if we can raise the freedom of a person who lives closed in their home, we can see tomorrow."*

4.2.3.2 Connectivity Through Social Media

Online networks and social media are the most chosen mediums for exchanging information between people with disabilities and organizations. For example, an online campaign was conducted by World Cerebral Palsy Initiative in 2012, which involved the question *change my world in a minute*. The participants of the campaign needed to share their idea that would help people with CP or disabilities in under a minute. *Participant 3* explains his experience of participating in the campaign:

> *"There was a global voting, resulted in my idea of solar powered electric wheelchair being number one, and accepted by the World CP association."*

The campaign being publicly open in an online environment allowed for the interaction of the participants and a communal evaluation of their ideas. Furthermore, the visibility that such a platform provides allowed the participant's idea to be seen by engineering students, prompting them to build a working prototype and connecting with the participant. *Participant 3* talks about the sustainability of such a connection after the campaign is complete:

> *"Sure, I'm still in contact with them on Facebook; if I wanted, I could write to them, but who knows, they might have their own families now, they grew up, it's been seven years..."*

Additionally, social media platforms are actively utilized to raise awareness of the general public. *Participant 5* gives details of an online collaboration he has prepared with another person who has CP:

> *"Around two hours ago we met with a friend with CP. She keeps working on the events every Saturday on Instagram. We prepared a program called events that ease the daily life of cerebral palsy. Working from these examples, if that eases some kids' lives, we will be relieved even if just a little."*

4.2.4 Nature of Experience with Abled and Disabled Communities

Involving in organizations and personal networks requires people with disabilities to interact with both other members of disabled communities, and the abled communities. The participants state positive and negative experiences they had in those interactions, which involves comments on the personal attitudes, the disability awareness of people, and the collaborations they had with them. For example, the comment of *Participant 1* illustrates that even the actions which seem to be positive could have negative connotations for people with disabilities:

> *"Of course, there are abled people in the association, even mostly them, people who have a close relative or a friend who is disabled are getting involved. They usually say I love it, respect it, and want to help, but they satisfy their own egos."*

4.2.4.1 Positive Experiences with Abled Communities

People with disabilities reported various types of positive experiences that they had during their interactions with abled communities. While some interactions are on a one-to-one personal level, some interactions are mediated by organizations. *Participant 4* recalls the positive interactions he had with the abled community through the art events organized by the social services of which he was a member:

> *"There are painting workshops, handcraft workshops... all sorts of workshops. The kids in social services spend quality time with those, they produce something, and there are exhibitions afterward, you become closer with the outside community."*

People with disabilities see various making activities as a positive way to spend their time. Furthermore, it can be argued from the above quote that the artifacts they produce in making activities act as platforms for positively engaging with the abled community. Apart from engaging with outsiders, disability-focused organizations such as paralympic sports teams make it possible for non-disabled people to join these disability communities, resulting in positive in-community experiences. *Participant 7* remarks on her satisfaction with her non-disabled community members:

> *"In terms of sports context, I don't have any problems because our team members, technical crew, and support people are well informed and supportive in every situation."*

In addition, some paralympic sports branches by their nature enable positive interactions between the abled and disabled. *Participant 8* emphasizes the uniqueness of the para-dancing branch:

> *"It is the only sports branch that an non-disabled person can participate together with a person with disabilities."*

4.2.4.2 Negative Experiences with Abled Communities

Although there are a considerable number of positive experiences reported by the participants, there are also as much negative interactions with the abled community. *Participant 1* explains the possibility of certain positive gestures from the non-disabled community being nongenuine:

> *"We see that a public officer is posing in front of the accessible bus to say we did it, it is an event for fooling the press actually, and most events like this are usually similar."*

Adding to the deceptive events, some people with disabilities encounter a lack of communication with the abled authorities about their problems, as *Participant 2* states:

> *"I need to use the subway; the opening and closing duration of the doors are very short and problematic. I acted and wrote to the city municipality about support, increasing the door durations; of course, it didn't solve a thing."*

Another form of negative experience that was present in the statements of association members was the suspicions of exploitation of the disabled community. *Participant 1* connects his leave from the disability association to this problem:

> *"That was also the reason I left these activities (the association) because the old president (who was non-disabled) was organizing stuff with the thought of getting profit from it from the shuttle drivers and the likes."*

4.2.4.3 Comparison Between Disabilities

Negative experiences are not exclusive to the interactions between the disabled and the abled. It is also observed that there exist apparent tensions between disability communities caused by the tendency to compare different disability groups. This can be in the form of comparing the legal advantages of each disability, such as the comment of colostomy bag user *Participant 6*:

> *"It isn't known as much as an arm or a leg... Of course, it's really hard to be disabled; this one is unknown and invisible to the outside. You live with it yourself by forgetting. It's legally a big problem if you think about it."*

Even when there is no comparison of advantages, *Participant 1* explains the tendency of disabled groups to show themselves as having more disadvantages than other disability types:

> *"The disability associations were gathering in Mersin, and they did a survey with us; one of the questions was which disability groups are the most disadvantaged, and there began a fight. Every group was racing for being the most disadvantaged like I'm the most, blinds are the most etc."*

4.2.5 Accessibility of Built Environments

Even more repeatedly stated, negative experiences were not about people or communities but about the overall accessibility of built environments in which the participants live. *Participant 4* talks about why the sidewalks need to be very suitable, not being made for the sake of it, with no bumps, not steep, and shallow to go over it:

> *"For example, we have a dentist here, they made a very nice ramp in front of it, but a little further in the pavement, there is nowhere to go up; I mean to be able to go there, another ramp is needed to be here at first."*

Although there is a positive attempt to improve accessibility from an abled member of his neighborhood when the infrastructure does not support this action. Moreover, the accessibility of the built environments, such as the physical places of disability associations, affects the participation levels of the association members.

Participant 6 explains the accessibility problems as the reason she didn’t physically participate in the association:

> *“(Talking about the association) it was also a difficult location to where I'm staying, I didn't go there myself, but people who need to go there, the nurses from those brands (who help with setting up the colostomy bags on patients) are also there.”*

4.2.6 Theme Relevance to Empowerment and Design Considerations

The abovementioned concepts under the theme of Communities, Social Activities & Built Environments can be evaluated in terms of their relevance to the empowerment of people with disabilities by utilizing Zimmerman’s *Empowerment Theory* (2000). The concepts found in the field research will be related to the three elements that the Empowerment Theory defines; being able to control and access resources, participating with others, and having critical awareness of the socio-political environment.

People with disabilities’ tendency to generate personal networks directly relates to the empowerment element of *participating with others*. For example, being in a collaborative process with international designers through a contest allowed *Participant 3* to communicate his user problems and the limitations that electric wheelchair users face to the people who can make design decisions for his wheelchair prototype. Moreover, the method of global voting for contestant ideas in this international contest empowered the participant to have a wide platform to explain his product dreams. As a result of this personal network and exchange of information with the designers, the participant was able to acquire a working wheelchair prototype, ensuring another empowerment element of *having access to resources*. In fact, *Participant 3* explains that he is not the only person who gained the ability to access this prototype resource, but actually, a whole community did:

> *"The intellectual property rights would be assumed by whoever realizes the project in real life, but this engineering team made a really nice gesture... they produced a prototype of my idea, they gifted that and sent it to me, and also transferred all of their intellectual property rights to the World CP Association."*

Continuing with the empowerment element of having control and access to resources, people with disabilities utilize their networks to access various skillsets that they personally lack but are necessary for modifying their assistive products. *Participant 4* talks about how he managed to adapt his electric wheelchair to have a sun-blocking roof accessory (see Figure 4.8):

> *"They are not professionals; there was a craftsman who did my house door, we are friends with him, he has a big network. I said I'll draw something like this. Do you know anyone who can make this?"*

Figure 4.8. The sunroof accessory (participant-designed, craftsman-produced).

It is important to note that, while utilizing his network to find a craftsman with skills for producing the accessory, *Participant 4* still maintains control over the process by providing the initial design through a drawing he made.

Apart from personal networks and the exchange of information, people with disabilities choose to participate in activities such as sports to physically empower themselves. As mentioned under the heading of *Involvement in Sports Groups* (see Section 4.2.2.2), the participants who are actively doing paralympic sports reported improved autonomy and independence by being fit enough to be able to do physically demanding tasks on their own. Additionally, as Participant 7 states, certain sports activities like swimming, by their nature, lift the user's movement limitations during the activity:

> *"When swimming, there is no problem; you don't think. I'll be so happy when swimming because it's the only field where you can work the entire body. You are free; there are no barriers in pools, in the sea, and you can do anything."*

Being enabled to control their environment both during the sports activity and later on in their daily lives by improved fitness renders involvement in sports an empowering activity for people with disabilities. With the help of their increased autonomy by involving in sports, people with disabilities become more aware of their capabilities and limitations in relation to other people in communities, corresponding to the third element of empowerment, *having critical awareness of the socio-political environment*.

4.3 Assistive Products, Making Activities & Environments

This theme investigates the product and making sphere of people with disabilities. This sphere includes the dimensions of the assistive products they use, their need for personalizing these products, how they are being used and shared, the dependence that the users form with the products, the problems of affordability, how the products are maintained, the regulations involving the assistive products, the users' dream product features, how much involvement the users have on the making of these products, and the actors in collective and creative production processes. Figure 4.9 illustrates the sub-themes under the main theme of Assistive Products, Making Activities & Environments.

Figure 4.9. The sub-themes of Assistive Products, Making Activities & Environments.

4.3.1 Dimensions of Assistive Products and Environments

People with disabilities use numerous assistive products and systems that change drastically in form and function depending on their specific type of disabilities. The study found that the users of assistive products would require personalising their products to fit their specific needs. Additionally, most participants reported using more than one product to assist them in their daily lives. While most of these products were used by only the participant, there are cases in which an assistive product is shared with multiple users. The need for sharing stems from the fact that some participants are having difficulties affording and accessing expensive assistive products. Moreover, the participants inevitably form dependencies on these highly specialized assistive products. That leads them to show great efforts of maintenance to improve the product life.

4.3.1.1 Personalization Need for Products and Environments

Participants emphasized the fact that each individual’s disability is unique in the sense of their abilities and their requirements from assistive products. *Participant 5* explains the impossibility of a one-size-fits-all product for users with CP:

> *“Cerebral palsy is a situation with many differences; another person with CP in the world, let alone in Turkey, is not like another person with CP. Their needs, inabilities, and abilities are almost completely different from each other. For example, a very useful product for me wouldn't work on another; that's why we have to generate more individual products or remedies.”*

It can be argued that different levels of the same disability group create needs for completely different assistive product types. For instance, *Participant 1* with paraplegia only needs a crutch to walk in his daily life, compared to *Participant 8*, who is also paralyzed but has to use a wheelchair. Moreover, even in similar levels of a disability group, the participants report the importance of a *physically fitting assistive product*. While talking about her discomfort with the older general-purpose wheelchairs that she used in her childhood, *Participant 7* emphasizes its importance for users’ health and wellbeing:

> *“If I answer it today, the wheelchair should be a perfect fit like shoes it should be supportive physically and healthy.”*

Additionally, the importance of ergonomics becomes much clearer when the assistive products are used in the competitive context of paralympic sports. *Participants 8* and *9,* who are partners in the paralympic dancing branch, explain that a para-dance wheelchair must be specifically made for the athlete:

> *“(Talking about the wheelchair) down to its wheels it is very different, it is also custom produced for an individual, produced for the person’s center of gravity, and according to their arm and leg lengths.”*

Personalization in paralympic sports is not only sought after for physical performance and perfect-fit, but also can be required for personal preferences. *Participant 7,* who is a paralympic archer, explains that her preference for holding her bow and arrow consequently affects the necessary products and accessories she uses during competitions:

> *"We need to find which position is the most comfortable to shoot from; most of our friends strap themselves to the wheelchair from their left side, I for example, like to take support from my right shoulder…"*

In addition to the personalization of the products and accessories, some people with disabilities might also require specific modifications to personalize their living environments. *Participant 7* is unique in the sense that she had the opportunity to build her home from scratch, tailored to her own individual and disability needs:

> *"(Explaining the construction of her house) Yes, exactly, because a standard-issue home wouldn't be suitable, as I said, because every disability is different and unique, we organized it (the house) in a way that I was comfortable.*

4.3.1.2 Use of Multiple Assistive Products

Participants have various special needs that arise from their disabilities, which sometimes can't be assisted with a single product. This need can be in the form of requiring different versions of the same assistive product type. For example, *Participant 7* states that she regularly uses three different wheelchairs in her daily life:

> *"I use a regular wheelchair at home… On the outside, I use an electric wheelchair. I go to the training by public transport… I switch to my (archery) wheelchair and do my training there."*

The same need for multiple wheelchairs is also apparent in the cases of *Participants 8* and *9*, where they use regular wheelchairs at home and a special wheelchair for dancing (see Figure 4.10):

> *“(Comparing his wheelchair with the para-dance one) No, it’s a different vehicle… because in terms of both maneuverability and overall weight, the wheelchairs we use in dancing are made of carbon (fiber), from the material of its seat to its wheels.*

Figure 4.10. Daily-use wheelchair (left), para-dance wheelchair (right).

Multiple assistive product usage is also seen in daily life contexts as well. *Participant 10* is the daughter of an elderly person who acquired several impairments to his sight, hearing, and motor abilities over the years. As she explains, her father uses many different assistive products that he needs to carry around with him:

> *"We have stress balls so he can work his finger muscles, his medications, he has special yellow glasses for better sight, telescopic glasses, magnifiers, watches... He needs something that can fit all that so he can carry them around on his own."*

As a result of having to use multiple assistive products, the participants might require packaging and carrying solutions to carry all of those assistive products together.

Also, people with disabilities might require using and trying out various versions and types of assistive products to find out which one assists them the best. *Participant 13,* who is a family member of a person with CP, has more than 30 years of experience with assistive products that his son uses:

> *"We changed tens of electric wheelchairs, we had two different parallel bars, but we couldn't manage to make him walk on his own. He used walkers 30-40 of them, maybe 50 of them."*

4.3.1.3 Product Sharing and Adaptation

The participants stated several motivations for sharing their assistive products with other people with disabilities. One of the motivations is to help other members of the same disability group by sharing their excess or unsuitable products. *Participant 6* explains how she tried to help other colostomy bag users:

> *"Ostomy Association in İzmir, there was Talat Bey. I had some product that I couldn't use, I called him to give it to someone who could use it. I was very sad, there was little kid born with closed intestines. I sent them my products, and that's how we help each other."*

While the act of sharing assistive products can be initiated with social motivations, it can also be involuntary and forced upon the user as well. The para-dancing partners *Participants 8* and *9*, emphasize their reason for using a singular wheelchair to be completely economic:

> *"We are working together as three dancers… One of us gets out, the other gets in, it (para-dance wheelchair) is not in much of a usable state, but right now, it is not a wheelchair that we can afford on our own."*

The affordability of para-dance wheelchairs also affects the performances of *Participants 8* and *9*, caused by the fact that during competitions both participants have to be on a wheelchair at the same time:

> *"Me and my partner compete in the duals category, there my partner sits on the para-dance wheelchair, and I have to dance in my regular daily wheelchair. It's a problem."*

Furthermore, not only the lack of a specialized wheelchair affects *Participant 8*, but because the para-dance wheelchair is custom-made for him, when *Participant 9* uses it in competitions, the ergonomic mismatch between her and the product causes additional problems:

> *"Of course, while my partner can maneuver this wheelchair with only his hips because the wheelchair is not made for my body proportions, I can't use this function."*

Users of assistive products also share novel adaptations or entire product ideas within their disabled community as well. *Participant 13* designed a walker for his child to use; his walker design has been tried and used by many children with CP at his son's school, where he helped with adjusting the dimensions and the height of the walker to fit with other kids:

> *"Dozens of kids there practiced with it (walker); they could walk. According to their ages, sizes and height changes, the walker needs to get higher or lower; I made these back then."*

In addition to sharing personal assistive products with each other, in public or community contexts, people with disabilities also use commonly shared products. *Participant 14* is an IT teacher in an inclusive high school that has students with various disabilities. She explains the shared products (see Figure 4.11) which the students use during class hours:

> *"In here, our classes have special computers that you can control with touch, and other than that, there are chairs and desks with a button for controllable height."*

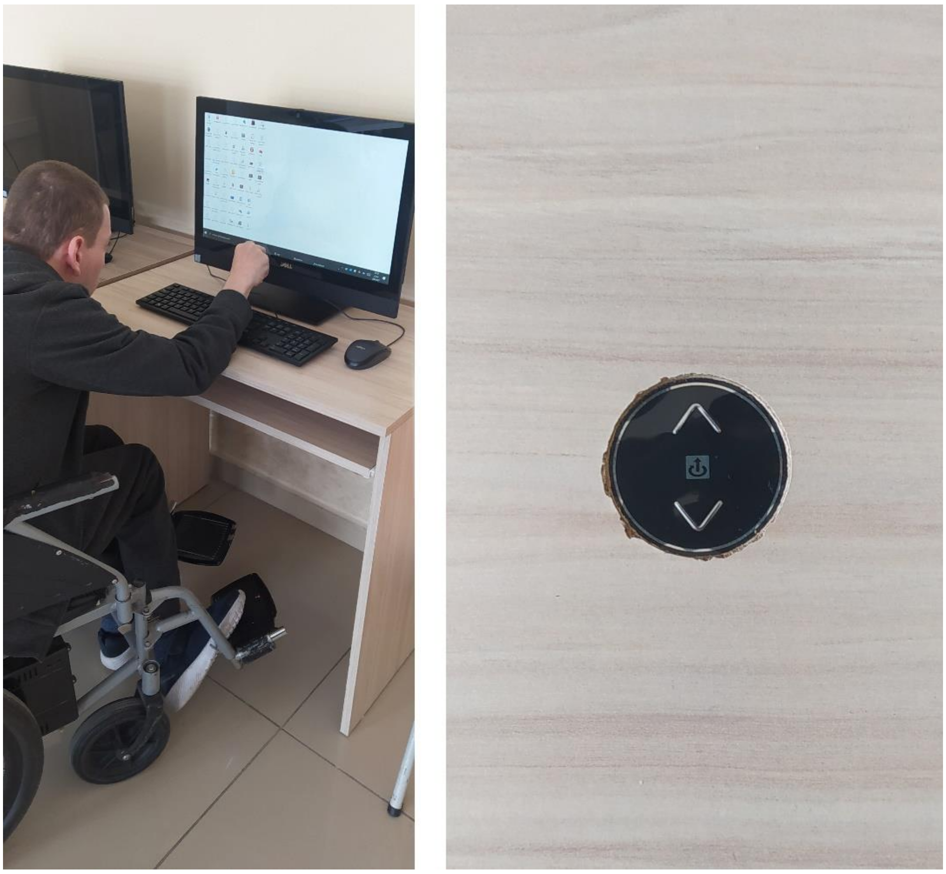


Figure 4.11. Touch-screen accessible computers (left), the height control button on another computer desk in the classroom (right).

4.3.1.4 Accessibility and Affordability of Products

Assistive products are a highly specialized product group that usually comes with high costs, consequently lowering their affordability. Having problems in accessing the required assistive products because of their high price is repeatedly reported by the participants. For example, during her initiation process with the product group of colostomy bags, *Participant 6* emphasizes the difficulties of acquiring her initial products:

> *"(Talking about her first colostomy bag experience) there were many problems... I also was giving too much price difference, coming to the hospital buying from the first brands they put after the operation."*

Lack of knowledge about the alternatives on the market led the participant to have problems with affording her assistive products. Even if the user has enough market knowledge, some product categories, such as wheelchairs, are inevitably expensive. *Participant 7* recalls needing to get organizational assistance in order to get her first wheelchair:

> *"I mean, the wheelchair was a luxury in my time; we didn't have the means to get one because my treatment was also expensive. I got my first chair through the association."*

The participant was part of a disability-related community specifically formed by other people with the same affordance problem. Such an association that provides wheelchair help to people who need it shows that some types of assistive products are expensive enough to require communal effort to get access. In fact, the socio-economic context of an individual with disabilities greatly affects their access to not only the actual assistive products but also their access to knowledge about these products. During the talks about her dream features of an electric wheelchair on her radio program, *Participant 12* points out the realization she had while discussing the features with other disability members:

> *“After doing the radio program, I realized that I was saying it’s 2022, so people should have read about this stuff (talking about voice control for wheelchairs). However, there are still people with disabilities who have never even seen an electric wheelchair in their life.”*

4.3.1.5 Product Dependency

People with disabilities form strong dependencies on their assistive products. It can be argued from the participant responses that the reasons for this dependence are the *highly specialized nature of the assistive products* and the *irreplaceable functions* they accomplish for the users. *Participant 3* explains in detail the most important disadvantage of using a wheelchair according to his experiences:

> “*I was saying there should be something so that I never left without a charge and could travel the whole city. Because for an electric wheelchair user that is the worst thing, the fear of going out of charge in the middle of the city. It's your legs, suddenly becoming immobile is really tough.”*

The user’s decision to pick an electric wheelchair instead of a regular one for daily use in the city stems from the advantages of the electric wheelchair’s more specialized features such as less effort from the user, traveling more comfortably, and to further distances. However, choosing the more specialized version of the assistive product also increases the *user’s dependence on the product’s features* as well. In addition, as *Participant 4* states, the resulting dependency leads the users to make greater efforts to maintain their products so that they can increase that product’s life:

> *“You make sure that the wheelchair is good before checking yourself. Because if it doesn't work, I can't do anything.”*

Furthermore, it is also argued by *Participant 11* that the dependency of people with disabilities on their products negatively affects the affordability of the assistive products on the market:

> *“The prices of the product we use will never be in discount because what would the people with disabilities like us do? They have to buy them, some people are exploiting our necessities.”*

Lastly, *Participant 7* emphasizes that there are also dependencies on certain modifications and accessories of general purpose assistive products in order to improve their ergonomics and overall comfort:

> *“Let’s say a thousand disabled people, at most a hundred of them have air cushion accessories, it is a crucial part that prevents pressure injuries from always sitting, not everyone can obtain it….”*

4.3.1.6 Maintenance Process

Users of assistive products are heavily invested in the processes of maintenance of their products. The need for product maintenance is reported to be caused by various reasons. *Participant 7* points to the general quality of the products as the reason for maintenance:

> *“(Talking about the wheelchair use in the last six years) Of course, it wasn’t the only wheelchair that I used; you can only use that standard-issue wheelchair for one or two years, then you have to repair or replace them.”*

In the cases of relatively longer-lasting assistive products such as electric wheelchairs, users report the act of maintenance as a necessity. However, the maintenance of assistive products can require special expertise and technical knowledge. *Participant 4* explains the difficulties of finding a suitable expert to do maintenance on his electric wheelchair:

> *“But finding a craftsman was really hard, because everyone we found said they couldn't make it, you can't find a craftsman who can do maintenance work on disability products, we can find a few, and they can only make like %60 of the job.”*

In addition, *Participant 4* also emphasizes that the reason for not being able to do the maintenance on his own is not only the lack of technical knowledge and skill but also how much certain assistive products *enable easier maintenance*:

> *"Some disabled friends can dismantle their own motors and send them to a technician. I don't have such a skill... some techy-minded disabled friends can open the whole wheelchair and control it. Also, my wheelchair has a closed hood, which is not easy to open up. Some other friends' wheelchairs have visible batteries, easy to dismantle; mine is a lot of work... some friends who can use their arms well can do their own maintenance."*

Additionally, *Participant 10* argues that the level of specialization and added features that a product has effects on its repairability:

> *"It felt difficult to be forced to either get a product repaired or replaced entirely, just because an additional function is broken on an otherwise working product that meets your needs."*

4.3.1.7 Detailed Dream Product Features

People with disabilities have in-depth user experiences with assistive products. Because of this, they also have specific and detailed features that they dream an assistive product would have. The dreams could be in the form of products with multiple functions, such as *Participant 1*'s idea of a crutch-bicycle hybrid:

> *"My dream is this, a foldable bicycle, when it folds it becomes like a crutch, you push it on its wheels, when you open it turns into a bicycle again, it was always my dream for around ten years."*

In addition to combining different product functions together, the participants also had dreams of *improving the usability and comfort* of their existing products. *Participant 6* explains the features that she would like her colostomy bag to have:

> *"For example, I go out today, need to tie my shoes, looking for a high place, but when it folds, it also right at the waist level... a more flexible form, less abrasive. Especially the adaptor part needs to be softer and more flexible because it stretches when it sticks to the body."*

Another example in which the participants add a function to improve usability is *Participant 3*'s dream of a wheelchair that he can call upon:

> *"Other than that, I would really like to have a remote-controlled wheelchair; if it had a remote, I could call it near myself."*

Not all user dreams are about the functionality of the assistive products. As it can be understood from the statement of *Participant 12*, some wanted features are completely aesthetic or add *increased interactivity* between the user and the product:

> *"I would love to have a colorful wheelchair that wouldn't lower my mood. I'd like it to be bright with lights and have a voice. I know it's silly but I didn't want to use a wheelchair as a kid, so I think that would have been helpful. We are going into the 2020s; why don't we add software to wheelchairs so it could tell me good morning, you traveled this far today, I'm tired charge me… it can make jokes to me."*

The reasons for these product dreams staying as dreams are repeatedly connected to the lack of time and motivation to realize them. *Participant 15*, a robotic team captain who participated in a national competition together with his disabled teammates, talks about his future project idea:

> *"As a project, it is called a grey device. I was thinking about it would connect to the world through the user's brain signals, but I couldn't have the time to start it yet because of school. I formed the idea from the earlier projects from the competition."*

4.3.1.8 Product Based Regulations

Numerous legal regulations are in place in regard to the acquisition, use, and adaptation of assistive products. To illustrate, *Participant 7* needs to use very specific products for para-archery competitions:

> *“We do have the archery wheelchair that we built according to the rules and standards, I also use certain accessories to shoot my arrows.”*

There are also state-supportive regulations to help people with disabilities to have access to assistive products. *Participant 12* explains how these systems work:

> “In 2018, I got it (the electric wheelchair) with the state help, but I don’t think it’s necessary because the state wants you to pay that help back in five years anyway.”

In the cases of the assistive products being novel ideas, regulations that protect design ideas also apply to assistive products. *Participant 14* designed an accessible keyboard (see Figure 4.12) for her students with disability that is currently in the legal process of patent application:

> *“Because the buttons in a regular keyboard are too small, we had to make a different keyboard with bigger buttons, and we worked on it… That design is in the patent application process, and it will come soon.”*

Figure 4.12. The patent-pending accessible keyboard prototype.

Lastly, the regulations unrelated to disability can indirectly limit the ability to adapt to the living environments of people with disabilities. Wheelchair users *Participants 8* and *9* explain why they couldn't alter their homes:

> *"Because they are renters, they can't make permanent accessibility adjustments to their home; they try to organize their furniture and appliances to provide easier access."*

4.3.2 Making Process & Activities

Participants are involved in numerous types of making activities where the result can be related to their assistive products, their living environments, or for completely recreational purposes. The participants reported being involved in creative activities both individually and as part of a community. A strong motivator to be involved in making activities is to adapt their assistive products for increased physical comfort. Additionally, when the participants felt inadequate in terms of technical knowledge and skills, it was common for them to seek an expert for the making of products or accessories. There was also a general dissatisfaction with the local production quality, leading the users to adapt and improve their products.

4.3.2.1 Involvement in Creative Production

The participants show a tendency to get involved in making or producing novel products and ideas. There are variations in the *level of personal involvement in making processes*, from fully participating in the physical making activities to giving feedback to the makers. For example, *Participant 4* explains that he was highly involved in producing art projects in his free time:

> *"I don't produce art anymore; we wrote a novel years ago waiting to be published... other than that, I have a YouTube channel doing voiceovers, poems. Just before you called, I read a poem and was going to publish it."*

Individually participating in a creative making activity is also seen in the context of assistive products. *Participant 13* points out that he designed and built a walker for his son by himself:

> *"I had designed a thing in the shape of a circle, I would put my son in it, he held it, they usually have cross walking where they can't put their steps straight, so I put a rod in the middle, I would put a tape on it, and he could walk comfortably."*

Although *Participant 13* is directly the maker in this process, his son, who has CP is reported to be passive in the designing process of the walker. Another example in which the person with disability is active in the making process could be the case of *Participant 5* with his accessibility solution:

> *"I can't use a pen, but I can easily use a keyboard and mouse. Now I made this layout that I can put sticky notes on, which I printed from the computer. When I type in the student's name and surname, and print it with the post-it*

> *placed on the paper, it prints on the post-it. I also made my own stamps with my name and signature. What I just told you takes 30 seconds."*

Although not related to a specific assistive product, personally developing these kinds of accessibility adaptations is also apparent in *Participant 10*'s case, where she produced adjusted versions of an existing product for her father:

> *"I prepared and printed them (calendars) myself for a while, but he wants to see ones that are hung on walls. He couldn't use them because there wasn't enough contrast, but I made them better by cutting, printing it bigger…"*

Furthermore, the users' self-perception of their skills affects how much they get involved in making activities. *Participant 3* evaluates his potential contribution to the production of the wheelchair to be low:

> *"They also have limited resources. I mean, the most I could say at that point would be the solar panels shouldn't be that big; I don't know how realistic that would be..."*

On the other hand, *Participant 12* stated that she didn't see herself as disabled and that the disability was mostly a mental concept. It can be argued that this perception allowed her to be highly active in the making process of an accessibility solution in her workplace:

> *"I asked my manager if it would be possible to build an elevator here. He said go and plan it, and I thought he was joking. I was stubborn about it and talked with the elevator repairman and convinced my manager to build it."*

4.3.2.2 Collective Community Production

Participating in making activities together as a community was a repeatedly observed strategy that people with disabilities would employ. The extent of the community in question varied among the participants; while some participated in making activities in small personal networks, some were part of bigger, more organizational making activities. *Participant 3* recalls the making process of his modified balcony as a group activity (see Figure 4.13):

> *"As I said, my father is an art teacher and understands this kind of work. We looked for a house for two years... we used to live on the 4th floor, it was really hard..., we bought this house, but when we were thinking about how to enter, we came up with the balcony entrance. My dad drew it himself, and we produced it with a metal craftsman. It's actually a relative of my father, and he made the welding, etc. ... It was made as a collective effort. It was very comfortable."*

Figure 4.13. The ramp adaptation for the balcony entrance.

It can be argued that forming small groups with the required skills and knowledge is deemed by people with disabilities as an effective method of making assistive solutions. However, *community-based production* is also practiced on organizational levels. *Participant 13* explains the collaborations that the high school of their association makes with other organizations:

> *“In there (the high school), we did projects with Türksat from time to time, we evaluate the projects of the students and the families, some teams from universities come and mentor kids in their projects.”*

As a combination of the two levels of collective production activities, smaller groups inside an organization can also participate in a making activity together. *Participant 14* talks about the details of their robotics team activities (see Figure 4.14):

> *“We 3D printed the parts on the side there we have printers, we made this robot over there, we designed the metal parts, cut them in the machine, we made the triggers as well.”*

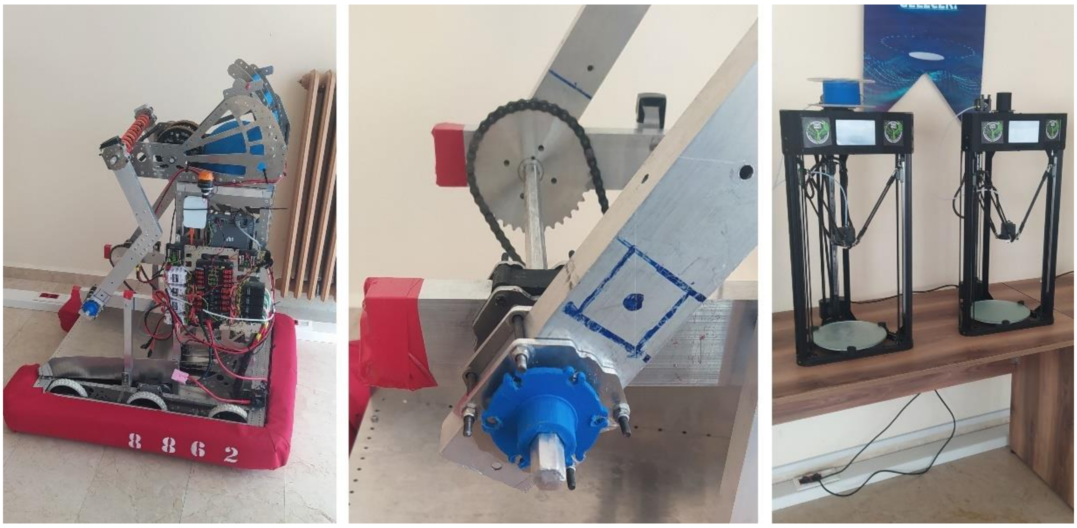


Figure 4.14. The robot built by the student team (left), some of the 3D printed parts (middle), and 3D printers in the school workshop (right).

Furthermore, *Participant 14* explains how the disabilities of the robotics team members directed how they planned the work division appropriately:

> *“(Talking about the students who worked on 3D printing) This kid can’t use one hand. This one is using a wheelchair, and she was managing the 3D printing of the parts… This kid uses a walker, and the other has a speech impediment, but they worked in the public relations (PR) group that*

> *presented our team. This kid with the walker helped in 3D too, and he can use his hands…"*

Besides, the participants who weren't involved in collective production activities also state their motivation and positive attitude toward the possibility of such activity. *Participant 10* explains that she is willing to work with designers collectively:

> *"If there was a communication network with the design departments of universities, if they said you want it and we'll take a look or trying to find solutions for the needs, and if there was something like that, I would love it."*

4.3.2.3 Adaptation for Physical Comfort and Personal Use

People with disabilities would require modifying and adapting their assistive products to improve their usability and make them more suitable for personal use. The process of adapting the product also varies for each case; while some participants are directly involved, others are giving the required instructions to others. *Participant 1* explains the process of how a regular automobile is adapted to be used without the use of pedals:

> *"It's like this, you buy a normal car and they put arrangements in it. You have to buy automatic transmission. Right now, I don't use my feet at all, I can just use my hands with the help of brake and gas arrangements."*

In this particular case, the participant can't have an active role in the adaptation process because of regulations and the expertise required for such an alteration in the product. As it can be seen in the statement of *Participant 5*, people with disabilities can also utilize their personal network to make adaptations to mass-produced products:

> *"(Talking about straws) They sent this in a pack of five, but they are all the same size, around 30cm. You can't put this inside a coffee cup... it would fall. I have a psychologist friend, also very interested in this cutting-making stuff. I give him the dimensions, and he made it into these lengths..."*

Moreover, there are many instances where the participants were personally involved in the adaptation of assistive products. For example, *Participant 7* has made a simple adaptation on her wheelchair to improve her comfort:

> *"Only, I attached a ragged tire to the ring of the wheels. Because I don't have enough movement and grasping in my hands, there is a special tire we use."*

Another adaptation example with a similar simplicity is the small modifications that *Participant 6* makes during her daily use of her colostomy bags:

> *"I mean, there isn't much I can do, but on my own... it needs to be very dry; it needs to be cut, everyone has a different intestine measurement. Should I cut a bit broader, should I put more paste or less...."*

The nature of this particular assistive product limits the level of adaptations that the user can apply. The complexity of the adaptation can also be higher than in this example. *Participant 13* talks about the modification he made on his son's wheelchair controls:

> *"Normally, the controls would be on the right side, but my son can't use them, so I moved that part to the back side of the wheelchair with an extension so that, I can control it from behind."*

Even though *Participant 13* defines this adaptation as a simple modification, it required using and processing additional materials and moving electronic components around. Additionally, the adaptation of a complex product can be in a simplifying direction. *Participant 3* explains that after a special feature of his prototype electric wheelchair stopped working, he modified the broken parts out of the product:

> *"Of course, because it was a prototype, there were some malfunctions, then we removed the solar panels and moved on to using it like that; I'm still using that vehicle."*

As this case illustrates, the *reversibility of the adaptations* made on the product is crucial for increasing the product lifespan. However, some products inevitably require replacements over time, and as *Participant 7* explains, the adaptations that are made on the old product can be problematic to transfer to the new replacement:

> *"Unfortunately, the accessories (e.g., shooting triggers that releases the arrows, archery bracers for holding the bow) we use gets deformed, and we need to replace them with brand new one. But, the precise calibrations and the fitting ability of the old ones are very hard to recreate exactly."*

On the bright side, some product types allow for *continuous adaptations* during their use. *Participant 7* explains how they keep an archery bracer accessory to fit the user's body perfectly:

> *"It was a reformable material if you put it on hot water. My trainer put it on the hot water again, then applied his own pressure on it, then we revised it to have the correct holding position and the pressure."*

The adaptations can also be made to the living environments of people with disabilities. *Participant 3* details the adaptations they made for his entry to his house:

> *"Our house is on the first floor, but the balcony is a little bit higher than the ground. We built a ramp into the balcony, I get up to the balcony through the ramp, then I get in the house. At the corner of the balcony, there is a cabin where I put my chair."*

Some adaptations needed to be made because of product sharing. *Participant 8* explains that to use his daily wheelchair effectively in the dancing competitions, he makes regular adaptations on his wheelchair to keep up with the dance-chair that he shares with his partner:

> *"I make changes in the wheels, in the ball bearings… I also change the straps, as much as I can."*

As a special case, *Participant 11* states that he doesn't need any adaptations on his horse-riding gear and uses the same product that non-disabled horse riders use:

> *"I don't need a special thing, really, because the horse I ride is specially trained; there is no need for special equipment than the regular riding saddles."*

In a sense, the need for adapting a regular product to fit the special needs of a person with disability is satisfied through an additional actor, a specially trained racing horse, that is *assistive* in itself.

4.3.2.4 Production Through an Expert

The participants report the processes of adaptation and overall production of assistive products to warrant the involvement of an expert. *Participant 3* emphasizes the importance he gives to finding the right expert to do maintenance on his product:

> *"The electrical system malfunctioned, I think it didn't work, then we found someone who understands these kinds of stuff. Because it's not right to let anyone tinker with the product, you can completely trash it."*

It can be argued that because assistive products are seen as precious and expensive, and because the users depend on them, choosing the experts who will produce or adapt the products is considered critical. Furthermore, the process of finding a qualified expert can also become arduous for the user, as *Participant 7* explains:

> *"They (the orthopedic specialists) try to produce some things completely through our directions. I tried 5 to 10 different ones until I produced a correct accessory."*

Because paralympic sports products and accessories (see Figure 4.15) are quite unique products, not many specialist producers can make them. According to *Participant 7*, this is the reason that paralympic athletes share their knowledge about these producers with each other:

> *"Yes, I shared it with them. My other teammates also got them produced from the same place. But for example, the men's category gets their accessories produced from a place in Ankara. I mean, everyone's choice is different because our disability levels are different."*

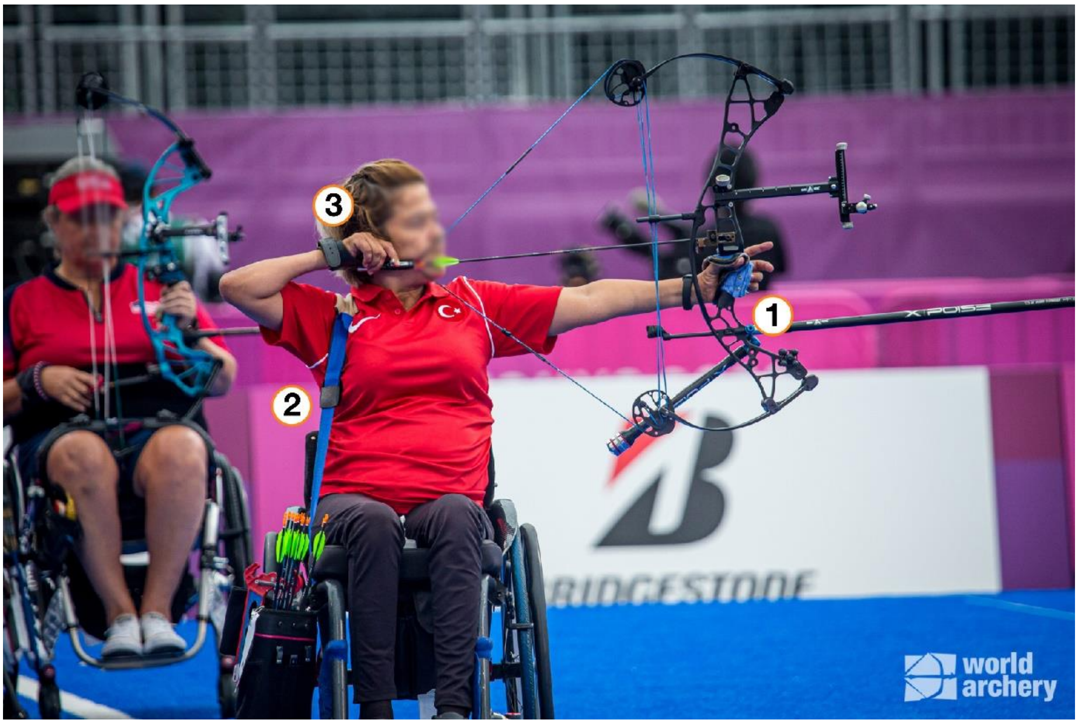


Figure 4.15. Para-archery accessories of Participant 7, (1) bow holder/wrist sling, (2) wheelchair strap, (3) release aid.

Note. Adapted from *World Archery*, by World Archery Federation, 2022 (https://worldarchery.sport/profile/39466). Copyright 2022 by World Archery Federation.

Furthermore, the specialist producers that work with paralympic athletes improve their knowledge and experience of sports products. Similarly, *expert makers* in other fields, such as watchmakers that *Participant 10* worked with to improve the visibility of her father's watches, also lack disability-specific experience:

> *"I mean, the craftsmen I talked to improve the watch said that they didn't have such a request before."*

Additionally, through working for special needs of people with disabilities, makers also improve their network of customers. *Participant 7* points out that she recommended the construction people she worked with while building her house to her other friends with disabilities:

> *"Yes, he did build other (accessible) houses too... I forwarded him to a friend of mine, and he built for her also... made new customers…."*

4.3.2.5 Local Production Quality

Some users are involved in producing custom solutions or adapting their existing products to better fit their needs because they are unsatisfied with the local production quality. While explaining her problems with local brands of colostomy bags, *Participant 6* states that she chose the brands for their quality:

> *"For long years, I use a brand called (Hollister), but there was an extra price because it was paid in dollars... Now I'm using Koroplast... as I said, quality is important, its durability, keeping up with your own body movements."*

She also states that she lacks knowledge about other product alternatives and their qualities outside the country:

> *"But you get uncomfortable when it gets bloated, and there can be stuff that is more comfortable. I only know the products in our country, and maybe outside there are better ones. I have no idea."*

Some participants reported knowing product alternatives abroad. *Participant 7* talks about the fact that she had to make many repairs and part replacements on her local wheelchair in three years and emphasizes the affordability problem of the products abroad:

> *"In the medical sector… local products are insufficient and low quality. Unfortunately, it is really difficult to afford European producers. As I said the prices are too expensive, even in the simple prosthetics if you want to get a good brand like Ottobock you have to pay a lot of money."*

Similarly, *Participants 8* and *9* reported the disadvantage they have in international competitions because of the quality differences in products:

> *"There are much better para-dance chairs with better materials and durability that dancers from other countries use in the competitions… I believe we should have these to represent our country as much as we can."*

4.3.3 Theme Relevance to Empowerment and Design Considerations

Similarly to the previous two themes, concepts under the theme of *Assistive Products & Environments & Making Activities* can be evaluated in terms of their relevance to the empowerment of people with disabilities by utilizing Zimmerman's Empowerment Theory (2000).

The statements regarding the need for personalization of the assistive products show the participants' intentions to improve their control over existing resources, consequently empowering themselves. The participants try to solve the problems in their interactions with the products by altering them to better suit their individual specific needs. Thus, the adaptations they apply to their assistive products also increase their control over their interactions, resulting in empowerment in their daily activities. Additionally, as discussed in the maintenance process heading, some assistive products empower the users by allowing them to tinker, enabling *easier maintenance* than other products. *Participant 1* emphasizes the empowering effect of the accessibility adaptations made on his automobile:

> *"Now, I have my own car too, so I don't have to deal with public transportation. It (being able to use his own car) has an immense advantage, and I could easily say I became %200-300 freer in the last five years."*

Furthermore, *Participant 3*'s experience of acquiring his prototype wheelchair (see Figure 4.16) is directly connected to the empowerment element of being able to access resources:

> *"I used the prototype around for a year, we (together with the engineering team) looked at how far it goes, how effective it is; I mean, it was perfect... I mean, you go a bit, and then it gets weaker, you stop, open the panels and wait 10 minutes, bam! It has power again, and it was a beautiful device."*

Figure 4.16. The usage of the solar panels on the prototype wheelchair.

Not only did the access to such a specialized assistive product greatly improve the participant's overall user experience, but the product was also a result of cooperation with makers, increasing the empowering value of the experience through the element of participating with others. Similarly, some participants' statements also point out how their involvement in creative production processes can be sought after only for the experience of participating with others, as *Participant 4* recalls:

> *"I contributed with painting. There might be thousands of paintings I made, most of them sold; I don't even have one. For me, it was not for exhibiting, but because meeting other people and painting felt good and helped me."*

Because the assistive products are used by people with special needs and disabilities, there are numerous regulations in place for them. The participants report the empowering effects that making use of such regulations has on people with disabilities. For example, as discussed in the heading of product-based regulations, following and utilizing the law changes regarding the waivers of taxes on vehicle purchases for people with disabilities allowed *Participant 1* to acquire an accessible automobile. This case can be an example of the empowerment element of having critical awareness of the socio-political environment.

Additionally, as discussed under the theme of *People with Disabilities* (see Section 4.1.7), there seems to be a proportional empowerment relationship between the concept of product dependency and the concept of independence from others. This stems from the *specialized nature of assistive products*. The more features and adaptations a product has, the more empowerment the user achieves through more control over the product. However, this comes at the cost of increased dependency on the assistive product.

It seems the motivation for increasing the specialization of assistive products is mainly to *improve their usability and comfort*. This in turn increases the users' *control* over the functions of their products, which indirectly improves their ability to *participate with others* by using their products, fulfilling two empowerment elements. It is observed that the most prominent approach to achieving specialized products is applying adaptations on them. In the scope of this study, two important features of empowering product adaptations emerged: *continuous adaptation*, and the *reversibility of adaptation*. If an assistive product allows for continuous adaptations while in use, it enables users to tailor the product features according to their changing needs and preferences (see Section 4.3.2.3). Secondly, when a malfunction or a deterioration occurs in adaptations, reversing those changes empowers the users to have control in using the specialized or the essential functions of their products (see Section 4.3.2.3).

Another aspect of adaptations and making activities that affects the achieved empowerment is the *level of personal involvement* of the user with disabilities (see Section 4.3.2.1). When the user is actively involved in the making or adaptation activities, they empower themselves through two elements: participating with others, as it is more than likely that there are other makers involved in the processes, and having control over resources, as they become the decision makers in what is being done on the products. However, reaching a high level of involvement is not always possible for every person with disabilities. When the making and adaptation processes are done on complex products such as electric wheelchairs or paralympic sports accessories, the users require specific skills and knowledge of expert makers. On the bright side, if this obligatory participation and communication between the expert makers and the users of assistive products is productive and effective, it can have greater empowering effects compared to if the users are trying to accomplish the making goals with insufficient skills on their own. Similarly, it seems when the activities of making and adaptation are done together as a community, users are empowered through participating with others who have various skills and knowledge required for the making activities (see Section 4.3.2.2).

Lastly, it was observed that the users were motivated in both making and adaptation activities to prevent the disempowering effects of the poor quality of local assistive products (see Section 4.3.2.5). They reported that local products like electric wheelchairs would get worn out or lose their charge very quickly, suddenly leaving the users immobile during the day. This forces the users to make adaptations on the product, such as adding an extra holder for a spare battery. This behavior is an example of users seeking to empower themselves by improving their control over the usability and lifetime of the product.

CHAPTER 5

CONCLUSIONS

This chapter connects the main findings and insights of the field research to the main and secondary research questions. As part of explaining the findings related to the research questions, the barriers and limitations in the current communities and making activities are discussed and given design considerations and insights that would make these problematic points more empowering for people with disabilities. Afterward, the limitations of the overall research are explained, and recommendations for future research is given.

5.1 Revisiting the Research Questions

This study has the main aim of investigating the needs and attitudes of people with physical disabilities regarding communities and making activities, and assessing their motivations and participation in the making, adaptation, and maintenance processes of their own assistive products. Disability is a relative concept that can be in the form of body function problems, activity limitations, or not being able to participate in a context (Persson et al., 2015). Designing for this particular user group aims to empower them, which can be reached by being able to control and access resources, participating with others, and having critical awareness of the socio-political environment (Zimmerman, 2000). Making activities in collaborative maker spaces (Bosse et al., 2018) provides an opportunity for empowerment through participation and resources.

Although there is a well-established literature on the interaction between maker activities and disability (Ellis et al., 2020; Alharbi et al., 2020; Hofmann et al., 2016), the focus remains on the cases where people with disabilities are passive feedback givers (Rogers & Marsden, 2013) and not active makers.

Because of the fact that the meaning of empowerment can be different for each person in various contexts (Zimmerman, 2000), understanding the personal perspectives of people with disabilities in a focused socio-economic context would contribute to the literature. Thus, this research study investigated the maker activities and communities from the personal needs and preferences of people with disabilities, particularly in the developing country context of Turkey. To reach this goal, the study utilized qualitative research methods to provide answers to the main and secondary research questions.

The main research question of the study was:

- What is the role of the making and collective production activities in enabling and empowering the participation of people with disabilities in designing, adapting and making their own assistive products?

The secondary research questions assisting the main question were:

- What are the implications of inclusive design and maker movement for enabling and empowering people with disabilities? *This secondary question is answered mainly through the review of the current literature. The rest of the secondary questions are mainly answered through the data from interviews and participant observations.*
- *People with Disabilities:* What are the individually specific needs and preferences of people with disabilities and their goals of independence from others?
- *Communities, Social Activities & Built Environments:* What are the reasons and motivations for individuals with disabilities to participate in or develop their own communities and making activities?
- *Communities, Social Activities & Built Environments*: What kinds of barriers and limitations are present in communities and making activities that people with disabilities face?

- *Communities, Social Activities & Built Environments:* How can the initiation and joining process of an individual with disability into a community or a making activity be supported/enabled?
- *Assistive Products, Making Activities & Environments:* What would be the design strategies that would empower these individuals with disabilities to develop their own assistive products?

The questions and related findings are discussed firstly from the secondary questions, in the order of the data gathered to answer them, starting from the initial secondary question.

What are the implications of inclusive design and maker movement for enabling and empowering people with disabilities?

Inclusive design aims to increase the usability and accessibility of products and services as much as realistically possible (BSI TBSI, 2005, as cited in Persson et al., 2015). The concept of inclusive design comes with the acknowledgment that it is not possible to design for every person and sets more accessible goals (Chamberlain & Yoxall, 2012). To reach inclusivity and accessibility in the designed solutions, the users’ needs, experiences, and preferences regarding their products need to be understood (Turhan et al., 2020). In the scope of this study, it could be argued that the inclusive design solutions that meet the needs and preferences of people with disabilities would have empowering effects. For instance, having more control over products and their functions would increase their participation in social contexts.

To truly include every person with individually specific disabilities, their unique needs and wants have to be communicated clearly during the design process of their products. The participatory design approach can be helpful in this regard as it aims to develop the solutions together with the end-users iteratively (Spinuzzi, 2005). By understanding the people with disabilities in detail through these participatory approaches, designers can develop solutions that would better include the users. In addition, this participation of the users can be improved one step further by allowing the users with disabilities to participate in the making and designing of their products.

Reviewing the current literature on the maker movement (see Section 2.2) reveals that there is considerable potential for the making activities to empower people with disabilities. Some of the examples involve 3D printing a prosthetic hand from open-source models in Thingiverse for users with missing fingers or modifying the controller stick of an electric wheelchair to improve its grip (Buehler, 2016). However, current applications for empowering the disabled community via maker activities focus more on placing the user with a disability in a passive role (Rogers & Marsden, 2013) in which the user only communicates their needs and feedback to the makers. Additionally, it is also reported that most of the current makers in various maker communities are dominantly non-disabled (Worsley & Bar-El, 2020). For the cases of research studies focusing on people with disabilities being the makers, participants reported a subjective sense of empowerment as the result of participating in making activities (Meissner et al., 2017). The source of empowerment can be different for each person; while some report empowerment through modifying objects and reusing materials, others are empowered by the making activity itself and sharing the ability to make objects with others (Roedl et al., 2015). Furthermore, the assistive products developed or modified via maker activities might see lower product-abandonment rates (Couvreur & Goossens, 2011).

Overall, both the general approach to inclusive design and the activities of the maker movement are influential in the empowerment of people with disabilities. However, current studies mostly investigate the accessibility of physical maker spaces (Bosse et al., 2018), participation of people with disabilities in short-term workshops (Meissner et al., 2017), non-disabled makers that make for people with disabilities (Hofmann et al., 2019), or maker activities in developed country contexts (Vandenberghe et al., 2022). Thus, as discussed under the heading *Significance of the Study* (see Section 1.3), there seems to be a lack of research on people with disabilities considering their personal journeys in communities and making activities, especially not focusing on their motivations, barriers, and interactions enough.

According to Zimmerman (2000), different people in different contexts can have considerably varying definitions of being empowered. This thesis study is conducted in the developing country context of Turkey, which provides the personal empowerment experiences of people with disabilities from the perspective of lower income communities, which is also lacking in the current literature.

What are the individually specific needs and preferences of people with disabilities and their goals of independence from others?

As explained under the heading *Individually Specific Disability,* people with disabilities are considerably unique and different from each other in terms of their abilities and limitations, even within the same disability group (see Section 4.1.1). These differences between individuals are more apparent in disability types such as CP, where the severity of impairments can change dramatically for every case (see Section 2.1.2.1). For example, many of the participants in the study were wheelchair users, but depending on their *individually specific disability* characteristics, some of them required additional products such as straws for drinking because of their limited motor abilities, while others could stand up and walk on their own for a couple of meters. As a result of this variation in individual abilities, the users require their assistive products to be *personalized* specifically to their needs. It seems this situation encourages people with disabilities to be more involved in the making and adaptation processes of their products. This is observed especially to be the case for paralympic athletes, as their sports success depends on their compatibility with their own assistive products and accessories.

The effects of the individuality of disabilities are:

- Inaccurate assumptions of a person's needs caused by the generalization of a disability group,
- The need for individualized or personalized assistive products,

- Motivation for people with disabilities to participate in the making and adaptation processes of assitive products.

Looking at the study's findings, the most prominent motivation for involving in the acts of making and adaptation is the need for personal *independence from others* (see Section 4.1.2). Additionally, the person’s ability to be independent of others is strongly connected to that person’s *self-perception*. In most cases, independence is gained through the use of assistive products. Consequently, less accessible and general-purpose products have disempowering, and more *accessible* and *personalized* products have empowering effects on the independence of people with disabilities. Lastly, it was also observed that as the person gets more independent from others with an individualized product, their *dependency on that product* increases proportionally as well (see Figure 4.4). For example, *Participants 3, 4, 7, 11, 12* and *13* are all users of electric wheelchairs, and their electric wheelchairs allow them to travel on their own independently. However, as many stated, the wheelchairs would lose their charge quickly and sometimes very suddenly during use, forcing them to be dependent on the help of others. Compared to a regular wheelchair, the electric wheelchairs that empower them to be more independent become immobile and limiting when they are out of charge because of the users’ increased *dependence* on the wheelchairs.

The next three questions are answered by the findings related to theme of *Communities, Social Activities & Built Environments*, which investigates the motivations, barriers, and initiation processes of various communities.

What are the reasons and motivations for individuals with disabilities to participate in or develop their own communities and making activities?

The study revealed two forms of community networking approaches that people with disabilities adopted, namely on *personal* and *organizational* levels. The most common form of community building is in the form of *personal networking* (see Section 4.2.1). It can be argued that people with disabilities opt for building relatively smaller personal networks in their communities because of:

- the less effort needed to initiate,
- the ease of building trust with the members, and
- the lack of an existing network or community for the specific need.

The participants reported aims and motivations for being involved in personal networks mainly are:

- needing to utilize individuals with particular skillsets that the person with disabilities does not have for certain making activities,
- *exchanging experiences and information* about their disabilities and assistive products, and
- being able to communicate their problems and needs to designers and makers.

People with disabilities are also involved with organizational communities (see Section 4.2.2). The motivations for participation are observed to change in accordance with the type of community, such as disability associations, government institutions, and sports groups. While disability associations and sports groups seek to meet others within the same disability group and *self-development*, people are involved in institutions to have legal rights and socio-economic assistance. Overall, the organizational networking motivations are:

- wider networking opportunities compared to personal networks,
- having access to opportunities for self-development,
- utilizing regulations and legal advantages that come with being a member,
- having a strong emotional bond and history with the organization, and
- the sense of fulfilling a debt to an organization that helped the person with a disability earlier in their life.

Apart from the motivations for community building and participation, the study also investigated the motivations of people with disabilities for developing or getting *involved in making activities* (see Section 4.3.2.1). In some cases, these activities are aimed at producing or adapting assistive products. The examples involve *Participant 4*'s sun-blocking adaptations on his electric wheelchair or the development of a solar-powered electric wheelchair prototype of *Participant 3*, while in others, they are aimed at recreational and art projects such as *Participants 1* and *4*'s painting and crafts activities in their disability associations. The motivations for involving in various making and adaptation activities are observed as follows:

- *personalization* need for assistive products,
- user's continuous maintenance efforts caused by their *dependence* on the products,
- difficulty in *affording* assistive products in the market, leading to more tinkering on the existing products to increase lifespan, and
- specific contexts requiring custom-made solutions to be produced (e.g., being involved in the production of an accessible elevator in the workplace).

What kinds of barriers and limitations are present in communities and making activities that people with disabilities face?

Throughout the personal journey of an individual with a disability in communities and making activities, the study explored and examined several barriers and limitations that negatively affect their participation. As seen in Figure 5.1, these barriers and limitations can occur in the stages of; initiation with the community or making activity, interacting with the other members and stakeholders, and during the making activities.

In the initiation stage of communities and making activities, the most common barrier was the lack of knowledge about the communities and makers. In the cases of organizations such as disability groups and associations, the people who recently *acquired* their disabilities had difficulties in finding out about related communities that would help them learn about and adapt to their assistive products (see Section 4.1.5). The lack of knowledge was also observed in creating *personal networks* with makers as well. Certain adaptations to existing assistive products and the production of specialized solutions, such as paralympic sports accessories, require technical skills and *expertise* that most participants report not having. The study revealed that the process of finding makers with suitable production skills and motivation was arduous for people with disabilities (see Section 4.3.2.4).

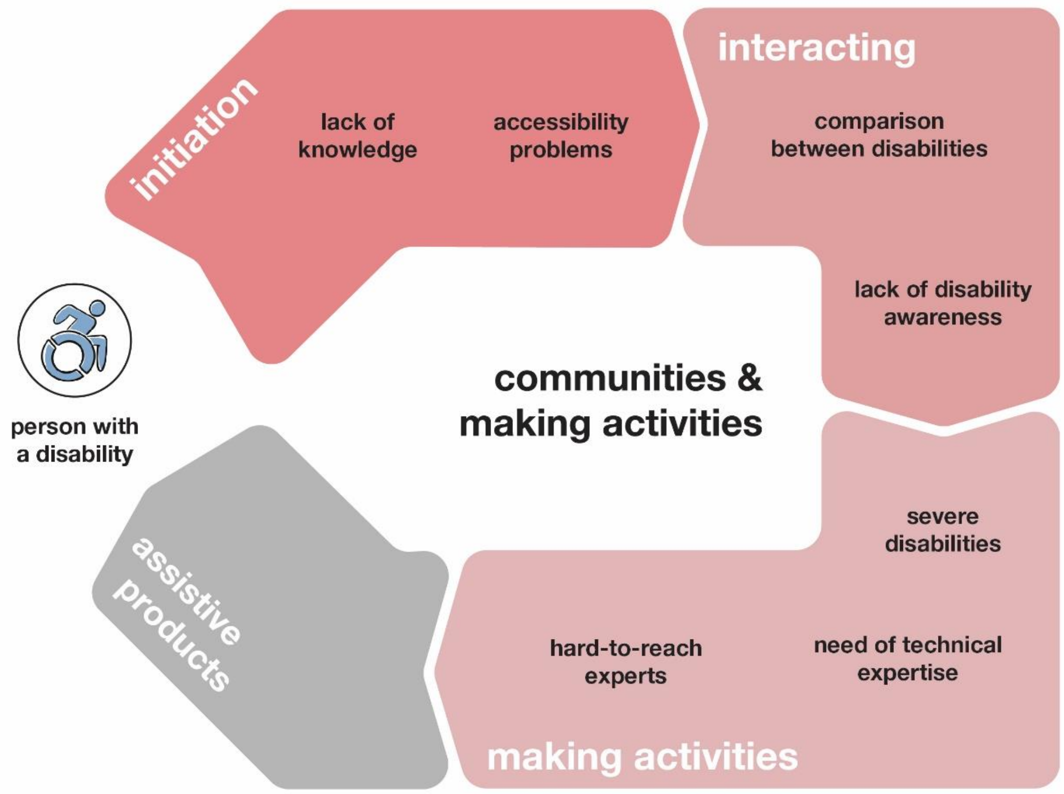


Figure 5.1. Barriers in existing community systems and making processes.

The participation in the community activities is affected by the *accessibility* of community places. If an association has a physical place in a part of the city with insufficient infrastructure and accessibility problems, people's participation in collaborative activities gets limited (see Section 4.2.5).

During the making activities and community involvement, there are barriers to the person's interaction with the other members and stakeholders. As discussed under the heading *Comparison Between Disabilities* (see Section 4.2.4.3), the most common source of the barriers between disabled members is the tendency to compare different disability groups with each other. This comparison can be in the form of understating the limitations of other disability groups while overstating their own limitations. Such tendencies of members with disabilities can be damaging to work divisions and decision-making in communities and during the making activities. When the interactions occur between members with disabilities and non-disabled members, the most prominent barrier is the lack of disability *awareness*. People with disabilities face difficulties during the making activities or community interactions when the non-disabled people do not have an accurate idea of their disabilities, capabilities and limitations, causing the making process to slow down and become inefficient with less ideal solutions.

Even when the interactions with non-disabled people and others with disabilities are not problematic, the study shows that there are still certain limitations in how a person with disability can participate in a making activity. For example, some form of disabilities and their severity can prevent a person with disabilities from personally machining and joining a steel profile, but, as some participants reported, inclusive division of the workload and objectives in relation to individuals' abilities does help in maintaining the participation of a person with disabilities in making activities.

How can the initiation and joining process of an individual with disability into a community or a making activity be supported/enabled?

As it is discussed above, there are many barriers in different stages of participating in communities or making activities. However, the barriers in the initiation stage take precedent as they can prevent newcomers from getting involved in the further stages altogether. As a result of this study, several recommendations can be put forward for enabling and supporting people with disabilities during their initiation stage in communities or making activities (see Figure 5.2).

Figure 5.2. Empowerment suggestions for the stage of initiation.

The most common initiation barrier was the lack of knowledge about communities and making activities, which might suggest the need for an effort from the communities side to provide information. Introductory events organized by disability and maker communities that can communicate their activities, who their members are, and how to get involved would be helpful to both inform the general public about these issues and attract newcomers with disabilities. These introductory events can also involve a maker side in the form of simple workshops that could be conducted in existing maker spaces to increase the making-related skills of people with disabilities and possibly gain them as new members. These events, which would be done in physical maker spaces, have the advantage of being an effective medium for the exchange of information by utilizing the maker objects as conversation-starters (Meissner et al., 2017). However, as the participants voiced their concerns on the *accessibility* of physical places, some potential members of such communities and making activities can have limitations to attending these introductory events. A widely used strategy by people with disabilities for communication and planning is observed to be the use of *social media platforms* (see Section 4.2.3.2). Thus, it can additionally be argued that utilizing the social media networks to introduce the communities and making activities to people with disabilities who are already active on social media would be fruitful. Additionally, after a person with a disability becomes a member of a maker community, they can act as disability ambassadors. This can arguably be done by promoting those members to conduct workshops with other disabled non-members, simultaneously improving the ambassador’s maker competency and gaining new members with disabilities into the maker community. Lastly, all of the above suggestions can be achieved through collaborations between existing disability associations and maker communities.

What would be the design strategies that would empower these individuals with disabilities to develop their own assistive products?

In the scope of this study, numerous cases are investigated where the person with a disability was involved in the *adaptation or making processes of the assistive products* they were using (see Section 4.3.2). The extent and the level of their participation in the making processes change considerably between each disability group and the products in question. Only a small number of the participants involved in this study was completely responsible for making or adapting their assistive products on their own, such as the system that *Participant 5* developed with printers and post-it notes to utilize keyboards instead of pen and paper to write messages. In most cases, the person with disabilities relied on the technical and physical help of others to participate in the making processes or was a bystander to the making activity entirely. As a result, it is clear that there is a need to empower people with disabilities to be able to control and participate in the making of their own assistive products.

To this end, some design strategies can be proposed involving people with disabilities, assistive products, and makers. Firstly, people with disabilities, like any user, start their relationship with assistive products as novices and require *the exchange of information* from more experienced assistive product users. The organic formations of *personal networks* aimed at these exchanges were reported during the study (see Section 4.2.1). Still, there were also cases where the person with a disability couldn't find the opportunity to interact with more experienced assistive product users, or they found those networks much later in their personal journeys. This finding can suggest that the promotion of *experience and information exchange* between users of assistive products is needed. When assistive product users get more knowledgeable about their products through these exchanges, their possible involvement in making or adapting those products becomes more likely.

Similar to the suggestion of using social media for community networking, utilizing people with disabilities' tendency to be active in online contexts, dedicated online platforms can be developed for more seasoned users of assistive products to share their experiences and novice user to learn tips related to;

- how they *personalize* their assistive products,
- which *expert producers and technicians* they cooperate with for producing or making adaptations on their products,

- their *dream features* of assistive products, and
- how to do *maintenance* on the parts of assistive products.

An online idea sharing platform with these focuses can allow the people with disabilities an easy access to; (1) expert user knowledge that is hard-to-reach conventionally, (2) an opportunity to share their wants and dreams about their products (as illustrated by the example of *Participant 3* on Section 4.2.1), (3) forming expert producer networks to produce, adapt, or maintain their assistive products.

It should be noted that there are already existing social media platforms and disability-related pages and groups. Still, the activity in these existing platforms are fairly low because not all disability associations have an online presence and activity on social media. Even the overall participation in associations is low (see Section 2.1.3.2). It could be argued that there are several reasons for this lack of participation from people with disabilities in existing online platforms:

- lack of trust in the overall social media platform, and the groups and pages under it, leading to questions about the authenticity of an online disability group,
- low visibility and accessibility of disability pages in general social media platforms with high numbers of pages and groups,
- people with disabilities not being convinced or aware of the possible benefits of being a member of disability groups on social media,
- lack of internet access, and
- the level of the disabilities of individuals preventing them from using digital devices.

Although the last two reasons can not be solved for the proposed online platform without improvements in overall infrastructure and digital accessibility solutions, a dedicated idea-sharing platform would increase the visibility and trustability of the online community for people with disabilities.

Apart from the online networking perspective, the study reveals that the openness of an assistive product is also crucial for people with disabilities to get involved in the adaptation or the making processes. For example, by providing a clear way for the users to understand and access the complicated inner parts of an electric wheelchair, the users can easily be a part of the *maintenance process* and reduce their *dependence* on a wheelchair technician, while a wheelchair with a closed and inaccessible hood over its engine limits the involvement of its user (see Section 4.3.1.6). Thus, important design consideration for assistive products would be to enable the user by providing *easier maintenance*.

Additionally, the maker communities can take an active role in empowering individuals with disabilities to be a maker of their own products. In the scope of maker communities, as discussed in the previous research question, participatory workshop events with disabled communities can be conducted where necessary maker skills and tools are taught to individuals with disabilities. This could be taken a step further, and disability-focused maker groups or community branches can be formed in which assistive products are the main interest. These communities can also organize idea competitions where people with disabilities that have severe limitations can participate in the making process through their *product dream ideas*, as this approach is observed to be empowering for the participating contestants (see Section 4.2.1).

Lastly, some design implications can be drawn from the participant observation in the inclusive high school. The school has a learning system that allows the interaction between students with disabilities and non-disabled students in participatory classes that involve making activities. Similar to the need for personalized products, students with disabilities are thought to have tailor-made education plans in which every student is expected to do tasks suitable for their *individually specific levels of disabilities*. Arguably, this personalized education process can also be applied to the participation of people with disabilities in design and making activities. For maker communities to develop personalized participation plans for their members with disabilities, people with expert knowledge on levels of disabilities and how to interact with each disability level need to be involved in maker communities, much like special education teachers who work alongside class teachers.

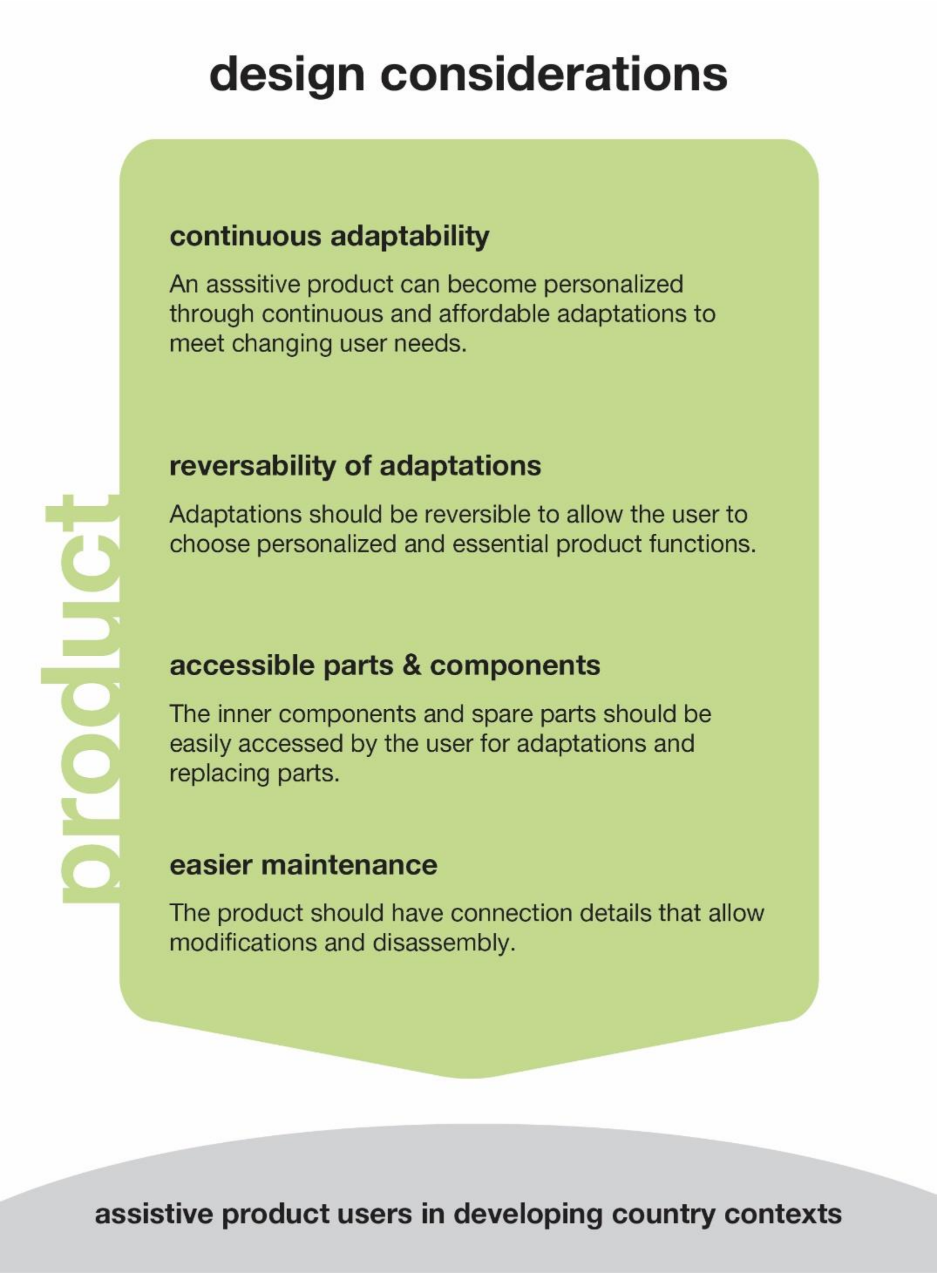
What is the role of the making and collective production activities for enabling and empowering the participation of people with disabilities in designing, adapting and making their own assistive products?

By relating the study findings with the secondary research questions, most perspectives of the main research question are discussed in the above sections. The empowering potential of making activities for people with disabilities is widely accepted in the literature (see Section 2.2.2). The approaches that put the person with a disability on the active maker position are relatively recent. Several cases of this study involved people with disabilities actively making or adapting their own assistive products. The *empowering effects* of their activities and products are analyzed in three spheres; *personal, social,* and *product* (see Sections 4.1.7, 4.2.6, and 4.3.3).

The intersection of *personal* and *product* spheres seems to be the most influential in the empowerment of people with disabilities. It is clear that disability and the limitations that come with it are highly *individually specific,* which consequently calls for the *personalization need of assistive products*. The fact that the assistive products are produced for general purposes motivates the users to get involved in personalizing their products. Looking at the study's findings, the individuals who adapted their assistive products in relation to their personal needs experienced empowering effects such as higher levels of *independence from others* and more control over those assistive products. For example, *Participant 7* had difficulties maintaining enough grip with her wheelchair on certain steep ramps. She explained that after she adapted the holding rings of her wheelchairs with an additional rubber lining, she could push herself on those steep ramps without needing another person’s help.

Making activities are seen to include people with disabilities at various levels and to different extents, which in turn also affects how empowered the individual gets through making. In the scope of this study, the most common form of participation in the making was communicating personal needs and overseeing the making process that is done by another person. For instance, in the case of *Participant 3*, he required easier access to his house, and people in his close-circle developed and built an entrance through their balcony (see Section 4.3.2.2). Although this level of participation ends up with a *specialized* assistive solution that empowers the user, the *dependence* on another maker can be limiting. In other cases, the act of making was done by a close family member or a friend, which proved to be more effective in reaching the result desired by the user as the interaction between the maker and the user was much stronger, continuous and iterative. This is exemplified by the walker design developed and made by *Participant 13* for his son with CP allowing him to walk and attend school on his own (see Section 4.1.2). In a few cases, the person with a disability was able to design, make, or adapt the solution on their own. Naturally, these cases had higher empowering effects on the users as they were in charge of the decisions and the final result. For example, *Participant 7* continuously adapted her archery bracer accessory while using it to achieve a perfect fit. However, this level of participation in the making process is not possible for every person with a disability, as some have severe limitations to their physical activities. Overall, if designed to effectively include people with disabilities, their close family members and friends, and as well as other makers, *collective production activities* have a high potential for empowering people with disabilities.

Lastly, as the concept of empowerment is closely related to the context it occurs in (Zimmerman, 2000), the findings of this study can also be looked at from the developing country context of Turkey. The most important effect of the context on the findings is the product-related decisions that people with disabilities make. The *production quality* of assistive products in the local market is on the low-end, leading users to search for alternatives (see Section 4.3.2.5). Because the alternative assistive products are imported and have higher quality, *accessing* and *affording* them becomes difficult for many people with disabilities (see Section 4.3.1.4). As a result of these socioeconomic limitations, the assistive product users in Turkey show a high tendency and motivation to prolong their assistive products' lifespan through *maintenance* and modifications. Consequently, this could be seen as an opportunity to promote making activities as a strategy to improve the *accessibility and affordability of assistive products*. As for the design of assistive products, adaptability (e.g., personalized, continuous, reversible, affordable, etc.), part replacement, accessibility of spare parts and inner components, and connection details that allow modifications and disassembly become important considerations for the users in a developing country context (see Figure 5.3).



continuous adaptability

An asssitive product can become personalized through continuous and affordable adaptations to meet changing user needs.

reversability of adaptations

Adaptations should be reversible to allow the user to choose personalized and essential product functions.

accessible parts & components

The inner components and spare parts should be easily accessed by the user for adaptations and replacing parts.

easier maintenance

The product should have connection details that allow modifications and disassembly.

Figure 5.3. Design considerations for empowering assistive products.

All in all, the empowering promise of making activities for people with disabilities seems to be apparent, especially in the socioeconomics of Turkey. However, currently, the promise looks to be underfilled as there is a need for developing necessary products, environments, and actors to empower people with disabilities to design, make and adapt their own assistive products.

5.2 Limitations of the Study

In this research study, I conducted semi-structured interviews and participant observations with people with various physical disabilities. The recruitment of participants through formal invitations to disability associations was ineffective in getting responses. Thus, I opted for snowball sampling with social media-active initial participants, which might have caused most participants to be highly motivated to participate and online active. Additionally, to reach a wide sample of paralympic athletes, applying for a formal research through Paralympic sports federations was time-consuming, so I personally contacted paralympic athletes who were active on online platforms. Paralympic athletes were not the sole focus of this research, and the small number of sports-related participants I recruited was enough for this particular thesis study. Still, for a future study with a paralympic athletism focus, wider recruitment through federations would be more suitable not to exclude athletes who are not active on online platforms. During the interviews, some participants had difficulties communicating their statements because of their speech impediments. As a suggestion for future studies, having the interviews with speech-impaired participants together with a close family member or a special education expert that can translate during the interview would increase the effectiveness of the conversation. As this was apparent in the participant observation at the inclusive high school with special education teachers who were helping the conversation.

I have reached my conclusions by retellings of participants' past experiences related to their communities, assistive products, and making activities. However, I did not have a chance to observe the act of making for a prolonged period, which would provide more accurate representations of the barriers and limitations that a maker with disabilities faces during a production activity, and the strategies they employ to overcome their limitations. The participant observation at the inclusive high school was insightful, which included accessibility-related solutions and adaptations and helped me triangulate data, and observe and understand the projects taking place in that context involving various stakeholders. Thus, repetition of such observations would increase the accuracy of the results. Additionally, in the scope of this study, established maker communities and their relationships with people with disabilities (if they had any) are not included, so the organizational barriers and challenges to include and empower members with disabilities are only represented from the individuals' perspectives.

As a final limitation, the field research phase of this study was mostly done during the Covid-19 pandemic conditions. This directed the research to online methods for sampling, recruitment and data collection stages. Although the online nature of most interviews eased the process of finding and convincing potential participants to get involved in the study, the effectiveness of the conversations would be higher in a face-to-face context which was experienced in the participant observation during the visit of the inclusive high school. The overall lockdown conditions during the pandemic also affected some participants' answers related to their participation in communities and making activities, as they couldn't get involved in them as much as before.

5.3 Recommendations for Further Research

To improve upon the current work, active involvement and observation during the making activities of people with disabilities would prove valuable. Participatory design workshops can be organized with established maker communities, disability associations, inclusive high schools, and designers. The role of designers in these workshops can be a combination of a facilitator and a maker. They can communicate the needs and wants of inexperienced people with disabilities to involve and engage experienced makers. The designers can also be actively involved in making groups to observe and manage the problems, strategies, and abled-disabled group dynamics first-hand. To understand the continuity of the workshops and their long-term implications or effects on the participants, a series of workshops that aim to track the change or real impacts of such collaborative activities might be valuable. This would also help develop practical design solutions by utilizing Research Through Design approach, building on top of the empowerment suggestions and design considerations generated in this study. Finally, analyzing similar approaches and studies or repeating the same approach in a developed country context would provide an opportunity for an accurate comparison of the effects of different contexts on empowerment.

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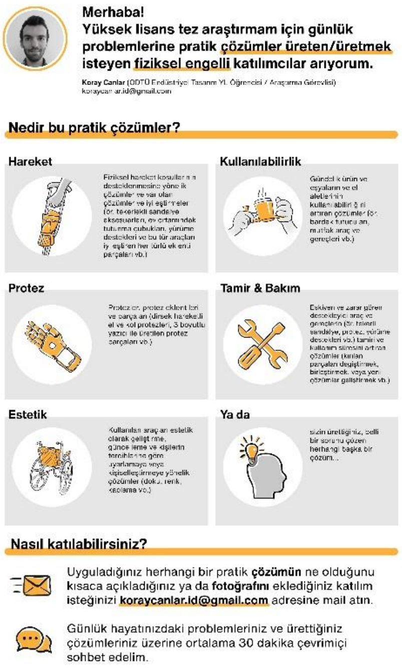
APPENDICES

A. Recruitment Poster Versions



Merhaba!
Yüksek lisans tez araştırmam için günlük problemlerine pratik çözümler üreten/üretmek isteyen fiziksel engelli katılımcılar arıyorum.

Koray Canlar (ODTÜ Endüstriyel Tasarım YL Öğrencisi / Araştırma Görevlisi)
koraycanlar.id@gmail.com

Nedir bu pratik çözümler?

Hareket
Fiziksel hareket koşullarının desteklenmesine yönelik çözümler ve var olan çözümler ve iyileştirmeler (ör. tekerlekli sandalye aksesuarları, ev ortamındaki tutunma çubukları, yürüme destekleri ve bu tür araçları iyileştiren her türlü eklenti parçaları vb.)

Kullanılabilirlik
Gündelik ürün ve eşyaların ve el aletlerinin kullanılabilirliğini artıran çözümler (ör. bardak tutucuları, mutfak araç ve gereçleri vb.)

Protez
Protezler, protez eklentileri ve parçaları (dirsek hareketli el ve kol protezleri, 3 boyutlu yazıcı ile üretilen protez parçaları vb.)

Tamir & Bakım
Eskiyen ve zarar gören destekleyici araç ve gereçlerin (ör. tekerli sandalye, protez, yürüme destekleri vb.) tamiri ve kullanım süresini artıran çözümler (kırılan parçaları değiştirmek, birleştirmek veya yeni çözümler geliştirmek vb.)

Estetik
Kullanılan araçları estetik olarak geliştirme, güncelleme ve kişilerin tercihlerine göre uyarlamaya veya kişiselleştirmeye yönelik çözümler (doku, renk, kaplama vb.)

Ya da
sizin ürettiğiniz, belli bir sorunu çözen herhangi başka bir çözüm...

Nasıl katılabilirsiniz?

Uyguladığınız herhangi bir pratik **çözümün** ne olduğunu kısaca açıkladığınız ya da **fotoğrafını** eklediğiniz katılım isteğinizi **koraycanlar.id@gmail.com** adresine mail atın.

Günlük hayatınızdaki problemleriniz ve ürettiğiniz çözümleriniz üzerine ortalama 30 dakika çevrimiçi sohbet edelim.

Merhaba!
Yüksek Lisans tez araştırmam için günlük problemlerine pratik çözümler üreten/üretmek isteyen fiziksel engelli katılımcılar arıyorum.

Koray Canlar (ODTÜ Endüstriyel Tasarım YL Öğrencisi / Araştırma Görevlisi)
koraycanlar.id@gmail.com

Nasıl katılabilirsiniz?

Sizinle paylaştığım **bağlantıya (link)** tıklayarak ulaşacağınız **kısa formu** doldurarak iletişim bilgilerinizi paylaşın.

Günlük hayatınızdaki problemleriniz ve ürettiğiniz çözümleriniz üzerine yaklaşık yarım saat sürecek çevrimiçi bir görüşme yapalım.

Nedir bu pratik çözümler?

Hareket
Fiziksel hareket koşullarının desteklenmesine yönelik çözümler ve var olan çözümler ve iyileştirmeler (ör. tekerlekli sandalye aksesuarları, ev ortamındaki tutunma çubukları, yürüme destekleri ve bu tür araçları iyileştiren her türlü eklenti parçaları vb.)

Kullanılabilirlik
Gündelik ürün ve eşyaların ve el aletlerinin kullanılabilirliğini artıran çözümler (ör. bardak tutucuları, mutfak araç ve gereçleri vb.)

Protez
Protezler, protez eklentileri ve parçaları (dirsek hareketli el ve kol protezleri, 3 boyutlu yazıcı ile üretilen protez parçaları vb.)

Tamir & Bakım
Eskiyen ve zarar gören destekleyici araç ve gereçlerin (ör. tekerli sandalye, protez, yürüme destekleri vb.) tamiri ve kullanım süresini artıran çözümler (kırılan parçaları değiştirmek, birleştirmek veya yeni çözümler geliştirmek vb.)

Estetik
Kullanılan araçları estetik olarak geliştirme, güncelleme ve kişilerin tercihlerine göre uyarlamaya veya kişiselleştirmeye yönelik çözümler (doku, malzeme, renk, kaplama vb.)

Ya da
sizin ürettiğiniz, belli bir sorunu çözen herhangi başka bir çözüm önerisi...

Merhaba!
Yüksek Lisans tez araştırmam için günlük problemlerine pratik çözümler üreten/üretmek isteyen fiziksel engelli katılımcılar arıyorum.

Koray Canlar (ODTÜ Endüstriyel Tasarım YL Öğrencisi / Araştırma Görevlisi)
koraycanlar.id@gmail.com

Nasıl katılabilirsiniz?

Karekod ile ulaşacağınız **kısa formu** doldurarak iletişim bilgilerinizi paylaşın.

Günlük hayatınızdaki problemleriniz ve ürettiğiniz çözümleriniz üzerine yaklaşık yarım saat sürecek çevrimiçi bir görüşme yapalım.

Nedir bu pratik çözümler?

Hareket
Fiziksel hareket koşullarının desteklenmesine yönelik çözümler ve var olan çözümler ve iyileştirmeler (ör. tekerlekli sandalye aksesuarları, ev ortamındaki tutunma çubukları, yürüme destekleri ve bu tür araçları iyileştiren her türlü eklenti parçaları vb.)

Kullanılabilirlik
Gündelik ürün ve eşyaların ve el aletlerinin kullanılabilirliğini artıran çözümler (ör. bardak tutucuları, mutfak araç ve gereçleri vb.)

Protez
Protezler, protez eklentileri ve parçaları (dirsek hareketli el ve kol protezleri, 3 boyutlu yazıcı ile üretilen protez parçaları vb.)

Tamir & Bakım
Eskiyen ve zarar gören destekleyici araç ve gereçlerin (ör. tekerli sandalye, protez, yürüme destekleri vb.) tamiri ve kullanım süresini artıran çözümler (kırılan parçaları değiştirmek, birleştirmek veya yeni çözümler geliştirmek vb.)

Estetik
Kullanılan araçları estetik olarak geliştirme, güncelleme ve kişilerin tercihlerine göre uyarlamaya veya kişiselleştirmeye yönelik çözümler (doku, malzeme, renk, kaplama vb.)

Ya da
sizin ürettiğiniz, belli bir sorunu çözen herhangi başka bir çözüm önerisi...

B. Recruitment Message

Turkish Version

Merhabalar,

Yürüttüğüm yüksek lisans tez çalışmam kapsamında, gündelik hayatlarındaki çeşitli problemlere pratik çözümler üreten veya üretmek isteyen, fiziksel engeli bulunan katılımcıların görüş ve önerilerini almak amacıyla araştırmama davet etmek istiyorum. Ne gibi çözümlerden bahsediyoruz derseniz:

- Fiziksel hareket koşullarının desteklenmesine yönelik çözümler ve var olan çözümler ve iyileştirmeler (ör. tekerlekli sandalye aksesuarları, ev ortamındaki tutunma çubukları, yürüme destekleri ve bu tür araçları iyileştiren her türlü eklenti parçaları vb.)
- Gündelik ürün ve eşyaların ve el aletlerinin kullanılabilirliğini artıran çözümler (ör. bardak tutucuları, mutfak araç ve gereçleri vb.)
- Protezler, protez eklentileri ve parçaları (dirsek hareketli el ve kol protezleri, 3 boyutlu yazıcı ile üretilen protez parçaları vb.)
- Eskiyen ve zarar gören her türlü destekleyici araç ve gerecin (ör. tekerli sandalye, protez, yürüme destekleri vb.) tamiri ve kullanım süresini artıran çözümler (kırılan parçaları değiştirmek, birleştirmek, yeni çözümler geliştirmek vb.)
- Kullanılan araçları estetik olarak geliştirme, güncelleme ve kişilerin tercihlerine göre uyarlamaya veya kişiselleştirmeye yönelik çözümler (doku, renk, kaplama vb.)

Bu tür ve listede olmayan her türlü farklı çözümlerinizi ve/veya gerçekleştirmek istediğiniz fikir ve hayalleriniz ile ilgili deneyimleriniz hakkında yaklaşık olarak yarım saat konuşmak, hikayelerinizi paylaşmak isterseniz koraycanlar.id@gmail.com adresinden veya (özelden, diğerden) bana(Koray Canlar) ulaşabilirsiniz. Şimdiden çok teşekkürler!

English Version

Greetings,

Within the scope of my master's thesis, I would like to invite participants with physical disabilities who produce or want to produce practical solutions to various problems in their daily lives to understand their views and suggestions. So, what kind of solutions are we talking about?

- Solutions to support physical mobility conditions and existing solutions and improvements (e.g. wheelchair accessories, grabbing bars in the home environment, walking aids and all kinds of accessories that improve such tools, etc.).

- Solutions that improve the usability of everyday products and items and hand tools (e.g. cup holders, kitchen tools and utensils, etc.)

- Prostheses, prosthetic attachments and parts (elbow, hand, and arm prostheses, prosthetic parts produced by 3D printing, etc.)

- Repair of all kinds of supportive tools and equipment (e.g. wheelchairs, prostheses, walking aids, etc.) that are worn out and damaged, and solutions to increase the duration of use (replacing broken parts, combining, developing new solutions, etc.)

- Solutions for aesthetically improving, adapting or personalizing the tools used according to people's preferences (texture, color, coating, etc.)

If you would like to talk about your experiences about your ideas and dreams that you want to realize and/or all kinds of different solutions that are not in this list and/or if you want to share your stories, you can contact me (Koray Canlar) at koraycanlar.id@gmail.com or (privately, from direct messages).

Thank you very much in advance!

C. Consent Form Sent to the Participants

Turkish Version

Bu araştırma, ODTÜ Endüstriyel Tasarım Bölümü yüksek lisans tezi kapsamında Koray Canlar tarafından yürütülmektedir. Araştırmanın amacı, fiziksel engelli bireylerin çeşitli üretim toplulukları ve/veya projelerine karşı olan tutumlarını, katılım seviyelerini, katılım süreçlerindeki elde ettikleri sonuçları ve geliştirdikleri çözüm önerilerini, bu sonuçları gündelik yaşamlarına ne derece dahil edebildiklerini, katılımlarındaki motivasyonları ve bu topluluklar / projeler içerisinde karşılaştıkları sorun ve kısıtları anlamaktır. Görüşme sırasında elde edilen veriler yalnızca bilimsel amaçlarla, tasarım sürecinde, tez çalışmasında, bilimsel yayınlarda ve sunuşlarda kullanılacaktır. Katılımcıların kimlik bilgileri saklı tutulacaktır. Konuşulanları ve süreci daha sonra tam olarak hatırlayabilmek ve gözden geçirebilmek için görüşme kaydedilecektir. Görüşme sırasında fotoğraf makinesi, video ve ses kayıt cihazı kullanılacaktır. Görüşme yaklaşık 45 dakika sürecektir.

Bu formu imzalayarak yapılacak araştırma konusunda size verilen bilgiyi anladığınızı ve görüşme yapılmasını onayladığınızı belirtmiş oluyorsunuz. Formu imzalamış olmanız yasal haklarınızdan vazgeçtiğiniz anlamına gelmemektedir; ayrıca araştırmacının, öğrencilerin, ilgili kişi ve kurumların yasal ve mesleki sorumlulukları devam etmektedir. Çalışmaya katılım gönüllülük esasına dayanır. Araştırma, katılımcılar açısından herhangi bir risk taşımamaktadır. Görüşme sürecinin başlangıcında veya herhangi bir aşamasında açıklama yapılmasını veya bilgi verilmesini isteyebilirsiniz. İstediğiniz zaman gerekçe belirtmeksizin görüşmenin durdurulmasını talep edebilirsiniz.

Araştırmaya katkıda bulunduğunuz için teşekkür ederiz. Araştırma hakkındaki sorularınız için araştırmacıyla ve danışman hocayla ile iletişime geçebilirsiniz. Aşağıda iletişim bilgilerine ulaşabilirsiniz.

Katılımcının Adı Soyadı	İmza	Tarih

Araştırmacı: Koray Canlar, koraycanlar.id@gmail.com

Danışman: Doç. Dr. Çağla Doğan, dcagla@metu.edu.tr

English Version

This research is being conducted by Koray Canlar as part of his Master's Thesis in METU Industrial Design Department. The purpose of this research is to better understand the attitudes and the participation levels of physically disabled individuals in maker communities and/or projects, the results of these making processes, the solutions they suggest, how much they can integrate these solutions to their daily lives, the motivations in their participation, and the barriers and problems they face in these processes. The data gathered during the interviews will be used just for scientific purposes, the design process, thesis study, scientific publications and presentations. The identity information of the participants will be kept confidential. To completely remember and analyse what was discussed, the interview will be recorded, either or both in video and sound. The interview will approximately last 30 minutes.

By signing this form, you acknowledge that you understood the information related to the research and approve to conduct the interview. The fact that you have signed this form does not mean that you give up your legal rights; in addition, the legal and professional responsibilities of the researcher, students, relevant persons and institutions continue. The participation in the research is voluntary. The research does not carry any type of risk for the participant. At any stage of the interview you may ask for explanations and further information. You can request for the interview to stop at any time without presenting a reason.

Thank you for contributing to the research. For further questions about the research, you can contact the researcher and the advisor. You can find their contact information below.

Participant Name and Surname Signature Date

Researcher: Koray Canlar, koraycanlar_id@gmail.com

Advisor: Assoc. Prof. Dr. Çağla Doğan, dcagla@metu.edu.tr

D. Interview Questions

Turkish Version

Kendinizden kısaca bahseder misiniz?

Kullandığınız yardımcı, destekleyici araçlar, aparatlar ve ara parçalar nelerdir?

- geçici ya da kalıcı olarak kullandığınız,
- ev ortamında ya da dışarıda kullandığınız,
- sizin uyarladığınız, dönüştürmek ya da ürettiğiniz veya yaptığınız,
- başkalarının sizin için uyarladığı, dönüştürdüğü ya da ürettiği veya yaptığı ürünler.

Topluluğa / Derneğe Katılım / Başlangıç

Bulunduğunuz topluluktan / projeden kısaca bahseder misiniz?

Bu topluluk ya da projede ne zamandır çalışıyorsunuz? Bu topluluğa ve proje katılımınız nasıl oldu?

Bu üretim topluluğunu/projesini hangi kanallar aracılığıyla keşfettiniz?

Topluluk / projeyle ilk iletişiminizi bireysel ya da sizin gibi yeni katılan bir grup üyesi ile mi gerçekleştirdiniz?

Topluluk / proje kapsamında yaptığınız ilk iş/projeden bahsedebilir misiniz?

Projenin amacı neydi?

Ne tür aşamalardan geçtiniz?

Ne tür araçlar ve yöntemler kullandınız?

Deneyiminizi nasıl değerlendirirsiniz? Proje süresince veya aşamalarında ne tür kısıtlar ve olanaklar vardı?

İyileştirmeye yönelik neler önerirsiniz?

Bu toplulukta / projede devamlı bir şekilde üretim etkinliklerinde bulunuyor musunuz? Tek seferlik bir üretim etkinliği miydi?

Nedenler ve Motivasyonlar

Bu topluluk / projede yaptığınız çalışmalardan bir gelir elde ediyor musunuz?

Çalıştığınız topluluk / projedeki sosyal ortamı nasıl tanımlarsınız?

Toplulukta / projede üretilen işleri bireysel kullanımınız amacı ile üretiyor musunuz?

Toplulukta / projede kendinizle aynı ya da benzer fiziksel engeli bulunan üyeler var mı?

Topluluk / proje gönüllülük esaslı mı? Bir devlet / belediye organizasyonuna bağlı mı?

Toplulukta / projede bulunduğunuz sürede ne tür ürünler / parçalar ürettiniz?

Bunları üretmekteki amacınız nedir? Hangi soruna karşılık bu üretildi, uyarlandı? Neden ihtiyaç duyuldu?

Bu süreçte kimler yer aldı? Projede kendinizle aynı ya da benzer fiziksel engeli bulunan üyeler var mı? Bir topluluk için de mi gerçekleşiyor? Projeyi destekleyenler var mı?

Proje içinde veya süreçlerde birden fazla kişi katkıda bulunuyorsa nasıl bir görev dağılımı var, nasıl katkı sağlıyorlar?

Fiziksel engel çeşitleri / seviyesi verilen ya da seçilen görev dağılımını etkiliyor mu?

Üretim, dönüştürme ekleme aşamaları neler? Hangi teknikleri ve araçları kullanıyorsunuz? Neler kullanıldı? Proje nasıl bir alanda gerçekleştirildi (ev, atölye, başka bir kuruluş, araştırma merkezi (Ar-Ge) vb.)

Bir üretim sürecinde öğrendiğiniz bir beceri ya da teknik var mı? Var ise bu becerileri sonraki üretim etkinliklerinde kullanma geliştirme şansınız oldu mu?

Tanımladığınız ya da deneyimlediğiniz probleme ne derece çözüm oldu?

Bu örneğin geliştirilmesi için önerileriniz neler? Neye ihtiyaç duyarsınız (malzeme, araç, kişiler vb.) Bu örneğin başka alanlar veya gündelik pratikler için uygun hale getirilmesi mümkün mü?

Çözümünüzü diğer paydaşlarla (sosyal medya, grupta engelli olmayanlarla) paylaşıldığı bir durum oldu mu?

Çözümünüz potansiyel olası diğer kullanıcılarla paylaşıldı mı?

Geliştirilmesini hayal ettiği çözümler ve çözüm önerileri var mı? (Genel değerlendirme sorusu)

Bariyerler ve Zorluklar

Bulunduğunuz toplulukta / projede fiziksel engeli bulunmayan üyeler mevcut mu?

Topluluk / proje içinde nasıl bir görev dağılımı var?

Fiziksel engel çeşitleri / seviyesi verilen ya da seçilen görev dağılımını etkiliyor mu?

Topluluk / proje fiziksel bir çalışma, toplanma mekanına sahip mi? Sahip ise ortamda üyelerin fiziksel engelleri için düzenlemeler mevcut mu?

Toplulukta / projede yapmayı, üretmeyi hayal ettiğiniz bir iş var mı? Şu ana kadar bu işe başlamanızı engelleyen bir durum var mı? Bu işin gerçekleşmesi için ne tür koşullara ihtiyaç duyuyorsunuz?

English Version

Can you briefly tell us about yourself?

What are the supportive tools, products and accessories you use?

- that you use temporarily or permanently,
- that you use in the home environment or outdoors,
- that you have adapted, transformed, produced or made,
- products that others have adapted, transformed, produced or made for you.

Joining / Starting a Community or an Association

Can you briefly tell us about the community / project you are involved in?

How long have you been working in this community or project? How did you get involved in this community or project?

Through which channels did you discover this production community/project?

Did you make your first contact with the community/project individually or with a new group member like you?

Can you tell us about your first work/project within the community/project?

What was the purpose of the project?

What kind of stages did you go through?

What kind of tools and methods did you use?

How would you evaluate your experience? What kind of barriers and opportunities were there during the project or its phases?

What would you suggest for improvement?

Do you engage in production activities in this community/project on an ongoing basis? Was it a one-off production activity?

Reasons and Motivations

Do you earn an income from your work in this community/project?

How would you describe the social environment in the community / project you work in?

Do you produce the works produced in the community / project for your personal use?

Are there members in the community / project who have the same or similar physical disabilities as you?

Is the community / project voluntary, affiliated with a state / municipal organization?

What kind of products/parts have you produced during your time in the community/project?

What is your purpose in producing them? In response to which problem was this produced or adapted? Why was it needed?

Who took part in this process? Are there members in the project who have the same or similar physical disabilities as you? Does it also take place in a community? Are there people who support the project?

If more than one person contributes to the project or processes, what is the distribution of tasks and how do they contribute?

Does the type/level of physical disability affect the distribution of tasks given or chosen?

What are the stages of production, transformation and addition? What techniques and tools do you use and what was used? In what kind of space was the project carried out (home, workshop, another organization, research center (R&D), etc.)?

Is there a skill or technique you learned in a production process? If yes, did you have the chance to develop these skills in subsequent production activities?

To what extent was it a solution to the problem you identified or experienced?

What are your suggestions for improving this example? What would you need (materials, tools, people, etc.) Is it possible to adapt this example for other fields or everyday practices?

Did you share the solution with other stakeholders (social media, non-disabled people in the group)?

Did you share the solution with other potential users?

Are there any solutions and suggestions for solutions that he/she imagines to be developed? (General evaluation question)

Barriers and Challenges

Are there members without physical disabilities in your community / project?

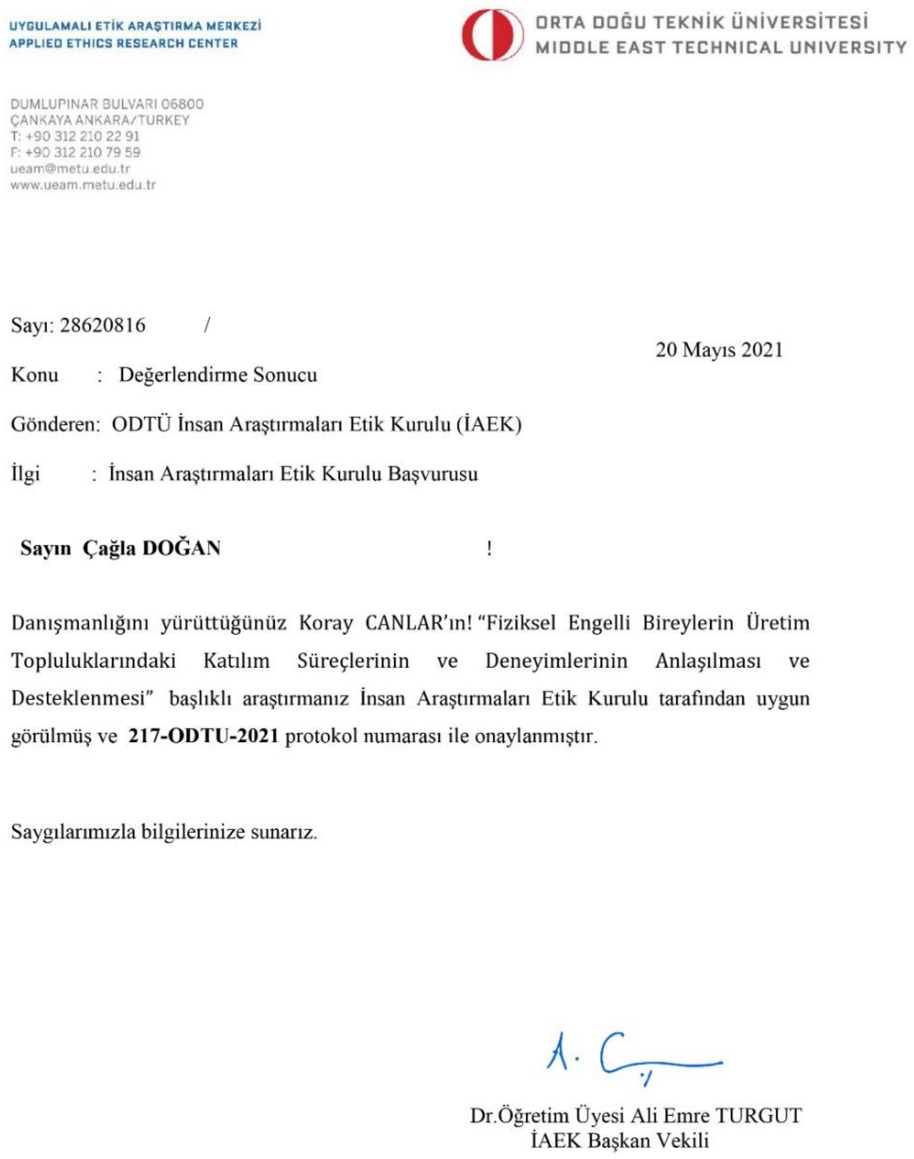
What is the distribution of tasks within the community / project?

Does the type/level of physical disability affect the distribution of tasks given or chosen?

Does the community/project have a physical working and gathering space? If so, are there arrangements for members' physical disabilities?

Is there any work you dream of doing or producing in the community / project? Is there any situation that has prevented you from starting this work so far? What kind of conditions do you need for this work to be realized?

E. Ethics Approval



UYGULAMALI ETİK ARAŞTIRMA MERKEZİ
APPLIED ETHICS RESEARCH CENTER

ORTA DOĞU TEKNİK ÜNİVERSİTESİ
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20 Mayıs 2021

Konu : Değerlendirme Sonucu

Gönderen: ODTÜ İnsan Araştırmaları Etik Kurulu (İAEK)

İlgi : İnsan Araştırmaları Etik Kurulu Başvurusu

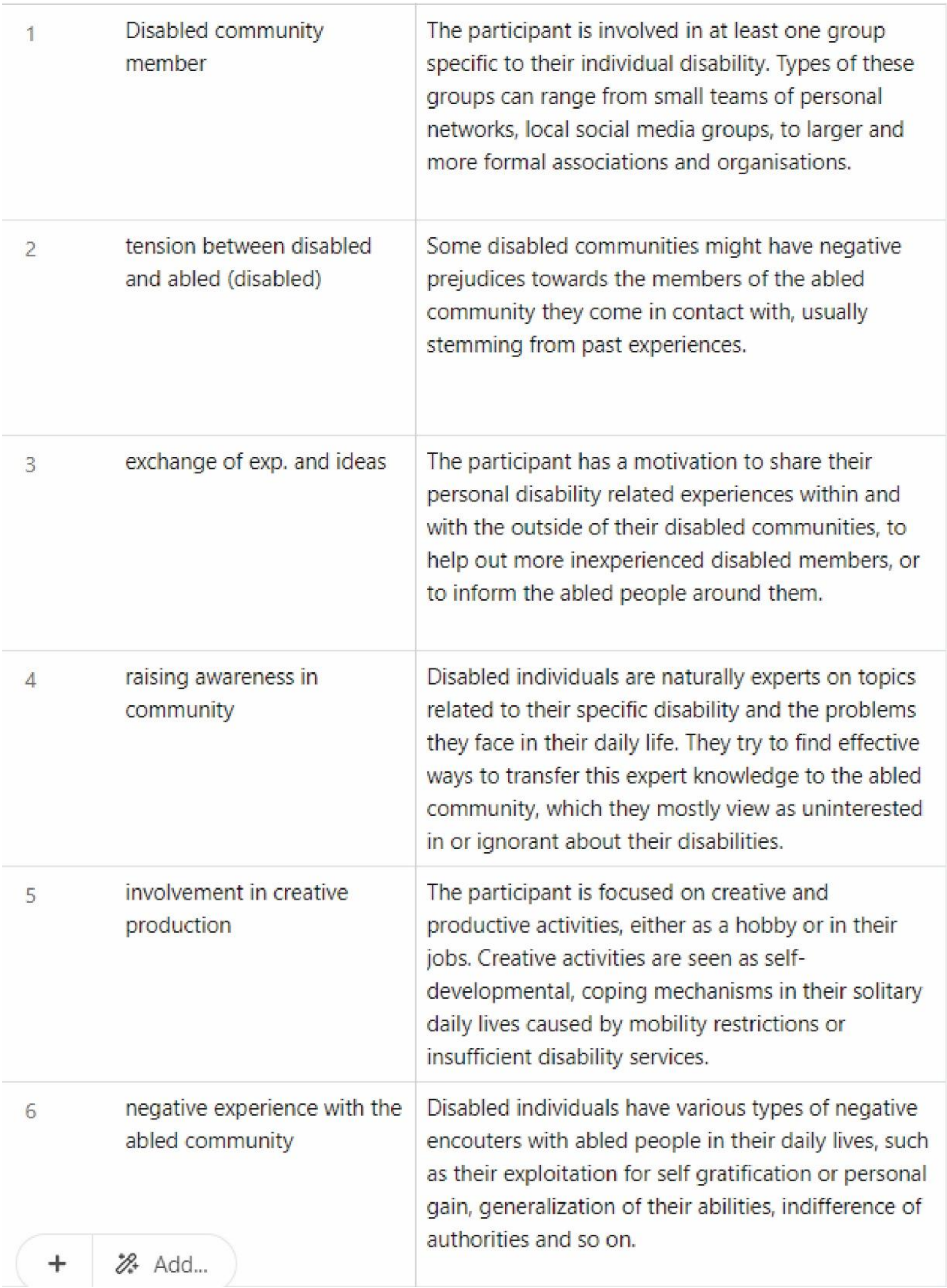
Sayın Çağla DOĞAN !

Danışmanlığını yürüttüğünüz Koray CANLAR'ın! "Fiziksel Engelli Bireylerin Üretim Topluluklarındaki Katılım Süreçlerinin ve Deneyimlerinin Anlaşılması ve Desteklenmesi" başlıklı araştırmanız İnsan Araştırmaları Etik Kurulu tarafından uygun görülmüş ve **217-ODTU-2021** protokol numarası ile onaylanmıştır.

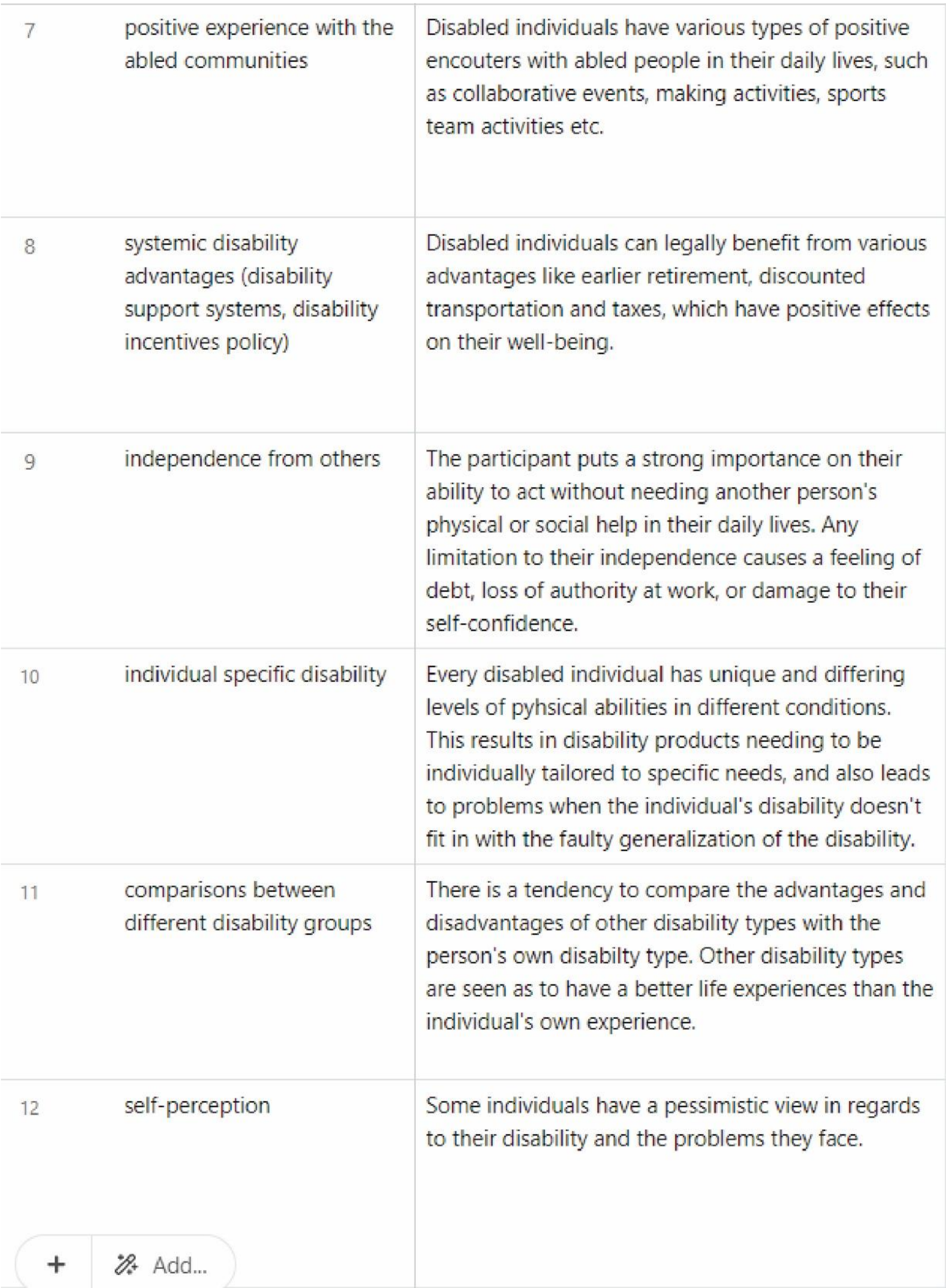
Saygılarımızla bilgilerinize sunarız.

Dr.Öğretim Üyesi Ali Emre TURGUT
İAEK Başkan Vekili

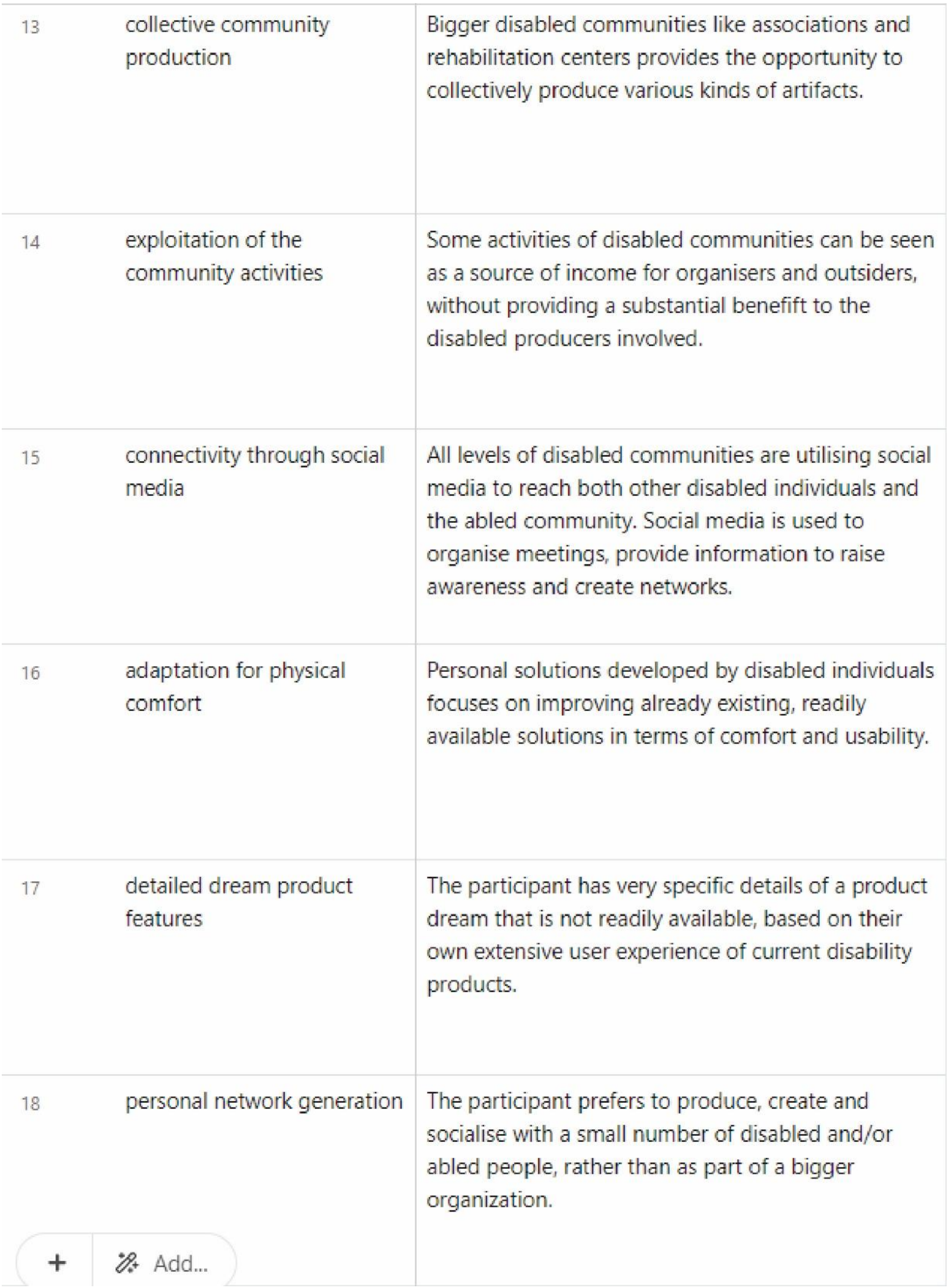
F. Glossary of Terms



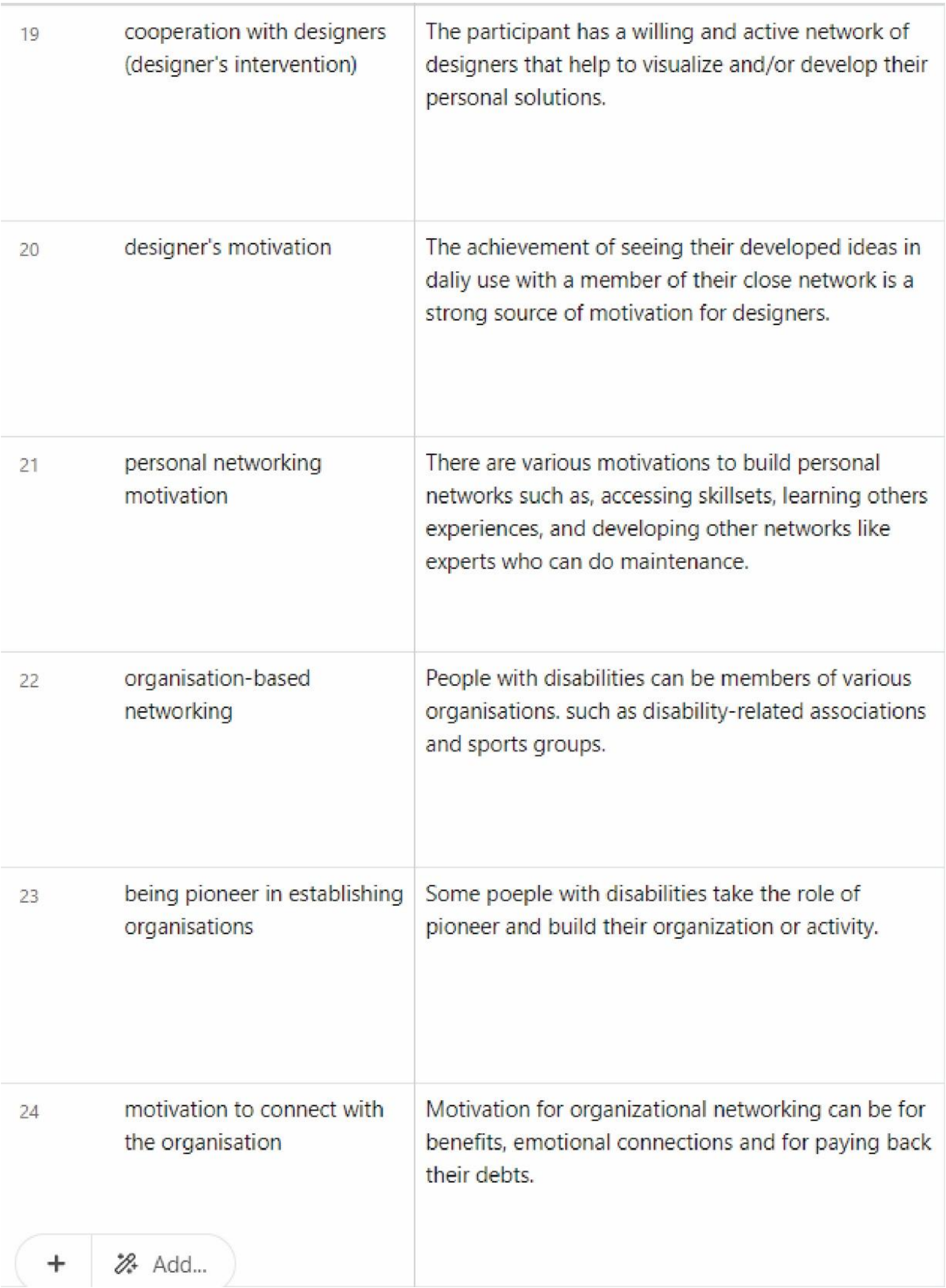
1	Disabled community member	The participant is involved in at least one group specific to their individual disability. Types of these groups can range from small teams of personal networks, local social media groups, to larger and more formal associations and organisations.
2	tension between disabled and abled (disabled)	Some disabled communities might have negative prejudices towards the members of the abled community they come in contact with, usually stemming from past experiences.
3	exchange of exp. and ideas	The participant has a motivation to share their personal disability related experiences within and with the outside of their disabled communities, to help out more inexperienced disabled members, or to inform the abled people around them.
4	raising awareness in community	Disabled individuals are naturally experts on topics related to their specific disability and the problems they face in their daily life. They try to find effective ways to transfer this expert knowledge to the abled community, which they mostly view as uninterested in or ignorant about their disabilities.
5	involvement in creative production	The participant is focused on creative and productive activities, either as a hobby or in their jobs. Creative activities are seen as self-developmental, coping mechanisms in their solitary daily lives caused by mobility restrictions or insufficient disability services.
6	negative experience with the abled community	Disabled individuals have various types of negative encouters with abled people in their daily lives, such as their exploitation for self gratification or personal gain, generalization of their abilities, indifference of authorities and so on.



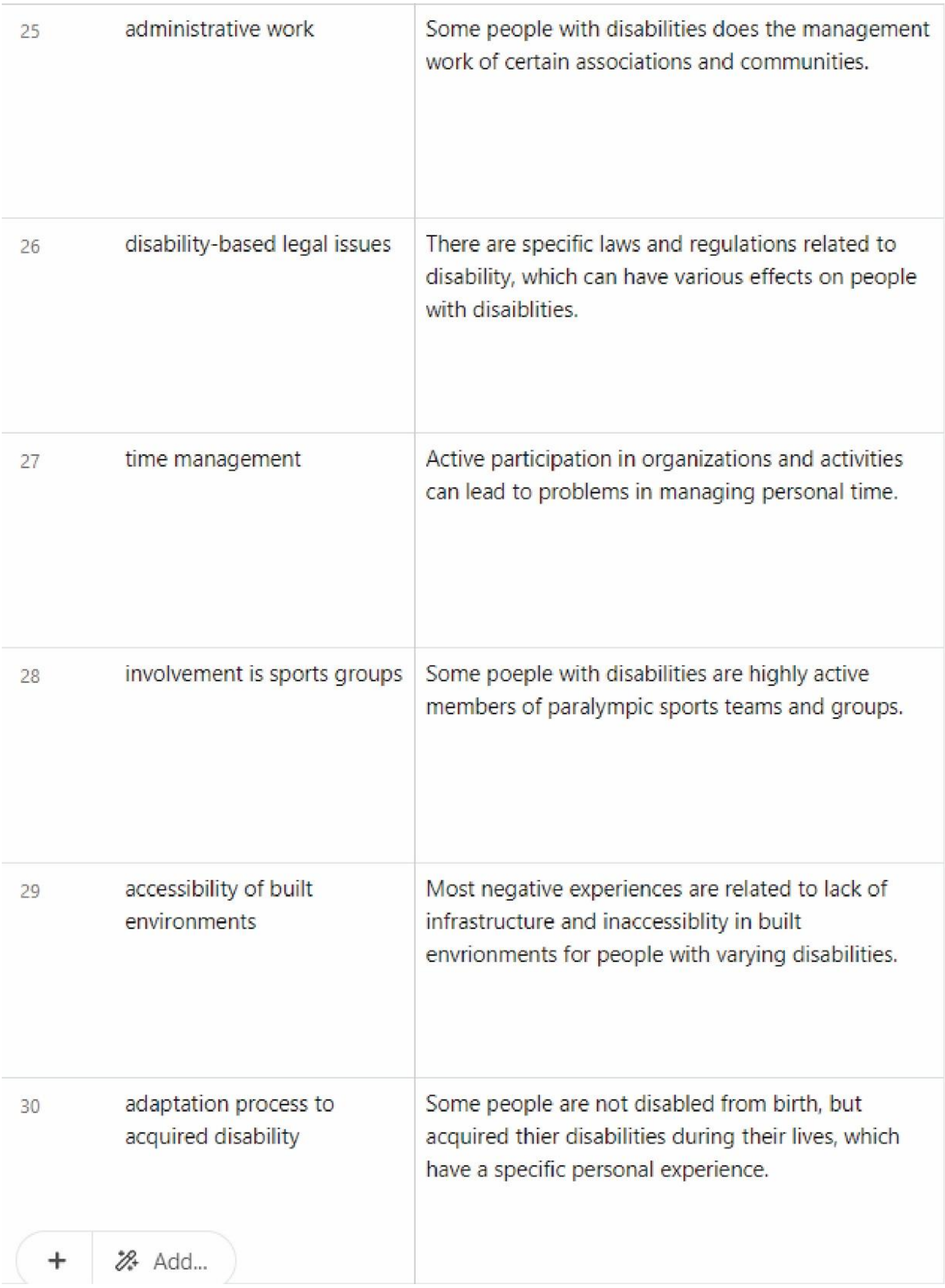
7	positive experience with the abled communities	Disabled individuals have various types of positive encouters with abled people in their daily lives, such as collaborative events, making activities, sports team activities etc.
8	systemic disability advantages (disability support systems, disability incentives policy)	Disabled individuals can legally benefit from various advantages like earlier retirement, discounted transportation and taxes, which have positive effects on their well-being.
9	independence from others	The participant puts a strong importance on their ability to act without needing another person's physical or social help in their daily lives. Any limitation to their independence causes a feeling of debt, loss of authority at work, or damage to their self-confidence.
10	individual specific disability	Every disabled individual has unique and differing levels of pyhsical abilities in different conditions. This results in disability products needing to be individually tailored to specific needs, and also leads to problems when the individual's disability doesn't fit in with the faulty generalization of the disability.
11	comparisons between different disability groups	There is a tendency to compare the advantages and disadvantages of other disability types with the person's own disabilty type. Other disability types are seen as to have a better life experiences than the individual's own experience.
12	self-perception	Some individuals have a pessimistic view in regards to their disability and the problems they face.



13	collective community production	Bigger disabled communities like associations and rehabilitation centers provides the opportunity to collectively produce various kinds of artifacts.
14	exploitation of the community activities	Some activities of disabled communities can be seen as a source of income for organisers and outsiders, without providing a substantial benefit to the disabled producers involved.
15	connectivity through social media	All levels of disabled communities are utilising social media to reach both other disabled individuals and the abled community. Social media is used to organise meetings, provide information to raise awareness and create networks.
16	adaptation for physical comfort	Personal solutions developed by disabled individuals focuses on improving already existing, readily available solutions in terms of comfort and usability.
17	detailed dream product features	The participant has very specific details of a product dream that is not readily available, based on their own extensive user experience of current disability products.
18	personal network generation	The participant prefers to produce, create and socialise with a small number of disabled and/or abled people, rather than as part of a bigger organization.



19	cooperation with designers (designer's intervention)	The participant has a willing and active network of designers that help to visualize and/or develop their personal solutions.
20	designer's motivation	The achievement of seeing their developed ideas in daliy use with a member of their close network is a strong source of motivation for designers.
21	personal networking motivation	There are various motivations to build personal networks such as, accessing skillsets, learning others experiences, and developing other networks like experts who can do maintenance.
22	organisation-based networking	People with disabilities can be members of various organisations. such as disability-related associations and sports groups.
23	being pioneer in establishing organisations	Some poeple with disabilities take the role of pioneer and build their organization or activity.
24	motivation to connect with the organisation	Motivation for organizational networking can be for benefits, emotional connections and for paying back their debts.



25	administrative work	Some people with disabilities does the management work of certain associations and communities.
26	disability-based legal issues	There are specific laws and regulations related to disability, which can have various effects on people with disaiblities.
27	time management	Active participation in organizations and activities can lead to problems in managing personal time.
28	involvement is sports groups	Some poeple with disabilities are highly active members of paralympic sports teams and groups.
29	accessibility of built environments	Most negative experiences are related to lack of infrastructure and inaccessiblity in built envrionments for people with varying disabilities.
30	adaptation process to acquired disability	Some people are not disabled from birth, but acquired thier disabilities during their lives, which have a specific personal experience.

31	self-development in skills	People with disabilities seek to develop their physical and social skills. They try to accomplish this self-development through community, making and physical activities.
32	personalization need for products and environments	The individuality of disabilities requires personalized assistive products tailored for each user.
33	product dependency	People with disabilities create strong dependencies with their assisitive products to achieve their daily functionns.
34	maintenance process	People with disabilities give importance to take care of their assistive products to increase their lifetime.
35	accessibility and affordability of products	Most assistive products are specialized and complex, which increases their production costs and price and lower their affordability by people with disabilities.
36	use of multiple products	Some people with disabilities have special needs that can't be met with a single assistive product, so they need to use multiple products.

37	product sharing and adaptation	People with disaiblities share their assistive products with each other because of high costs or helping fellow people with disabilities.
38	product-based regulations	There are various legal regulations related to the acquisition, use, and adaptations of assistive products.
39	local production quality	The assistive products that are produced in Turkey is experinced to be low-quality.
40	production through an expert	Because the assistive products are usually complex, adapting and maintaining them requires an expert producer/maker.