AN INQUIRY INTO THE NECESSITY OF PARTICIPATION OF PEOPLE WITH DISABILITIES IN ARCHITECTURE

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ABSTRACT

AN INQUIRY INTO THE NECESSITY OF PARTICIPATION OF PEOPLE WITH DISABILITIES IN ARCHITECTURE

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In the second half of the 20th century, disability rights advocates criticized society and authorities for considering disability as personal misfortune and inferiority and for not taking any responsibility for the struggle of people with disabilities. Those critiques developed a new perspective, the *Social Model of Disability*, affecting disability studies, rights, and policies. The Social Model defined *disability* as the outcome of the interaction between a person with impairment and the social and built environment. This definition supported that the inequalities in reaching opportunities, being prevented from participating in society, and the lack of representation constructed the negative image of the disabled identity. Moreover, the continuance of the existing organization reinforced the given identities and resulted in ignorance rooted in society toward disability rights. Therefore, the social model claims that disability is a socio-political concern and aims to change the role of people with impairments from dependent patients to active members of society who define the disability, the disabling barriers, and the wishes of disabled people.

However, a limited number of participants represent people with disabilities in all fragments of society, including the architectural profession. With the ideas that (a) architectural knowledge is developed with experience-based progress and (b) the

problems in achieving barrier-free design may be caused by the lack of diversity in the profession, this study aims to discuss the possibility that people with various bodily experiences may contribute to architecture in making a shift towards designing *enabling environments for all*. Therefore, a contextual inquiry was conducted to find the parallelisms and connections between different pieces of literature concerning disability, society, and architecture. Lastly, those relations were visualized with the mapping technique.

Keywords: Social Model of Disability, Design for All, Participatory Design, Differently-Abled Architects

ÖZ

ENGELİ BULUNAN BİREYLERİN MİMARLIK DİSİPLİNİNE KATILIMININ GEREKLİLİĞİ ÜZERİNE BİR ARAŞTIRMA

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20. yüzyılın ikinci yarısında toplum ve yetkililer, engelliliği kişisel bir talihsizlik ve aşağı bir durum olarak gördükleri ve engellilerin mücadelesinde sorumluluk almadıkları için engelli hakları savunucuları tarafından eleştirildiler. Bu eleştiriler, engellilik çalışmalarını, haklarını ve politikalarını etkileyen yeni bir bakış açısının, yani Engelliliğin Sosyal Modelinin geliştirilmesine sebep oldu. Sosyal Model, engelliliği; engeli bulunan bir kişi ile sosyal ve inşa edilmiş çevre arasındaki etkileşimin sonucu olarak tanımlamaktadır. Bu tanım, fırsatlara ulaşmadaki eşitsizliklerin, bireyin topluma katılımının engellenmesinin ve temsil edilmemesinin engelli kimliğinin olumsuz imajını inşa ettiği fikrini desteklemiştir. Ayrıca, mevcut toplumsal yapılanmanın devam ettirilmesi, verilen kimlikleri pekiştirmiş ve toplumun engelli haklarını yok saymasına yol açmıştır. Bu nedenle sosyal model, engelliliğin sosyo-politik bir mesele olduğunu iddia eder ve engelli bireylerin toplumdaki rollerinin, bağımlı hasta konumundan; engelliliği, engelleyici bariyerleri ve engellilerin isteklerini tanımlayan aktif toplum üyeleri konumuna değiştirilmesini hedefler.

Ancak, mimarlık disiplini de dahil olmak üzere toplumun tüm kesimlerinde engelli bireyleri, sınırlı sayıda katılımcı temsil etmektedir. (a) Mimari bilginin deneyime dayalı olarak geliştiği ve (b) engelsiz tasarım elde etmedeki sorunların meslekteki çeşitlilik eksikliğinden kaynaklanıyor olabileceği düşünceleriyle, bu çalışma, farklı bedensel deneyimlere sahip bireylerin, mimarlık disiplininin, *herkes için tasarıma* doğru gelişim göstermesine katkıda bulunabileceği fikrini araştırmaktadır. Bu kapsamda, engellilik, toplum ve mimari ile ilgili farklı alanlardaki tartışmalar üzerinde, aralarındaki paralellikleri ve ortaklıkları bulmak amacıyla bağlamsal bir araştırma yapılmıştır. Ve ardından, ortaya çıkarılan ilişkiler haritalama tekniği ile görselleştirilmiştir.

Anahtar Kelimeler: Engelliliğin Sosyal Modeli, Herkes İçin Tasarım, Katılımcı Tasarım, Farklı Yeteneklere Sahip Mimarlar

to my family

and to all oppressed people of this world

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LIST OF ABBREVIATIONS

ADA	American Disability Act
ADAPT	American Disabled for Accessible Public Transit
AIA	The American Institute of Architects
ANSI	American National Standards Institute
BCDOP	British Council of Organizations of Disabled People
CAP	Campaign Against Patronage
CAT	Campaign for Accessible Transport
CCDA	the California Commission on Disability Access
CIBFD	Canadian Institute of Barrier Free Design
CIL	Centre of Independent Living
DAN	Direct Action Network
DBA	Design Business Association
DDA	The Disability Discrimination Act
DIA	Disabled in Action
DIG	Disability Income Group
DPI	Disabled People's International
ECA	the European Concept for Accessibility
EDRA	Environmental Design Research Association
HHC	Helen Hamlyn Centre

ICIDH	International Classification of Impairments, Disabilities, and Handicaps
IDEA	the Center for Inclusive Design and Environmental Access
IL	Independent Living
ISO	International Standards Organisation
İTU	İstanbul Technical University
KU	Katholieke Universiteit
NY	New York
PD	Participatory Design
POE	Post Occupancy Evaluation
RCA	Royal College of Art
RIBA	Royal Institute of British Architects
TSE	Turkish Standards Institution
UD	Universal Design
UIA	The International Union of Architects
UN	United Nations
UK	United Kingdom
UPIAS	Union of Physically Impaired Against Segregation
U.S	United States
USA	United States of America
WHO	World Health Organization

CHAPTER 1

INTRODUCTION

> *Disability is not personal misfortune or individual defect, but it is the product of disabling social and built environment.*
> *Siebers, 2008b*

According to *World Health Organization (WHO),* "disability is part of being human". Almost more than one billion people, approximately 15% of the world's population, experience a form of disability, and this number is increasing because of the aging population and chronic health conditions (WHO, 2020). Although, in today's world, disability is defined as a public issue, it is known that throughout history, it was mostly seen as a personal tragedy (Oliver, 1990).

1.1 Historical Background

1.1.1 The Models and Definitions of Disability

While tracing the idea of personal tragedy in history, it is seen that societies tended to associate disability with different states such as vulnerability, unfitness, moral weakness, shame, sins, punishment, a divine response to parental wrongdoing, God's dismay, predestination (Barnes, 1995; Goodley & Swartz, 2016; Burcu, 2020). Although rare, some positive views of disability, such as being gifted and being touched by God, were seen in different cultures (Barnes, 1996). When those impressions are examined, it can be said that morality, religious views, and cultural beliefs affected how societies approached disability (Stone, 1995; Barnes, 1996; Snyder & Mitchell, 2001; Erkılıç, 2017).

Another view in history in which disability was individualized is the Medical Model, attributing disability to individual biological conditions. The models of disability are the ways the ideas about disability were translated into practice (Oliver, 2004), and according to the idea of the medical model, impairment is a sort of inferiority, malfunction, pathology, and deviance in human anatomy, and disability is being unable to perform tasks because of that impairment (Priestley, 1998; Terzi, 2004; Smart & Smart, 2006). Those conditions are considered to be individual and medical in this model; this is why they are seen as problems which are needed to be cured or rehabilitated (Oliver, 1990; Albert, 2004; Smart & Smart, 2006; Burcu, 2020) "to be as normal as possible" (Finkelstein, 1989, p.5). This view of disability had prestige and strength because of its relation to the profession of medicine; this strength resulted in both the public and individuals with disabilities have come to see disability as a pathological category (Smart&Smart, 2006; e.g., Parsons, 1952). Even in the definitions given by the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), which is the organization that WHO issued for the classification of the consequences of diseases and their implications, the effect of the medical model was seen. The definitions given by ICIDH and WHO (1980, p.14) were:

> (a) Impairments (I code), concerned with abnormalities of body structure and appearance and with organ or system function, resulting from any cause; in principle, impairments represent disturbances at the organ level.
>
> (b) Disabilities (D code), reflecting the consequences of impairment in terms of functional performance and activity by the individual; disabilities thus represent disturbances at the level of the person. […]
>
> (c) Handicaps (H code), concerned with the disadvantages experienced by the individual as a result of impairments and

> disabilities; handicaps thus reflect interaction with and adaptation to the individual's surroundings.

WHO was criticized by disability rights advocates and organizations that are controlled by people with disabilities, including the *British Council of Organizations of Disabled People (BCDOP)*, *Disabled People's International (DPI)*, and the *Union of the Physically Impaired Against Segregation (UPIAS)*, for equating disability with impairment (Albert, 2004; Thomas, 2011) and for paying insufficient attention to social and cultural factors (Burcu, 2020).

In 1976, UPIAS established a definition of disability as a radical alternative to the individualized medical conception and stated that "disability is the product of social organization rather than personal limitation" (see also Hunt, 1981). The political and intellectual arguments of UPIAS resulted in a turning point in defining disability (Finkelstein, 1991) and produced the baseline of a new model (Oliver, 1990; 2004). At the time, Mike Oliver used and elaborated on this new view of disability in his post-graduate course at the University of Kent in Canterbury (Oliver, 2004). According to Oliver, previously, the issue of disability had not been studied even in sociology, the discussions were left to the discipline of medicine, and the responsibility of disability was carried only by the person with an impairment (Oliver, 1996a; 1996b). So, he used the term "individual model" to refer to previous understandings of disability (Oliver, 1981; 1996a; 1996b). He presented his ideas about how society is responsible for the problems disabled people have in the world, firstly in 1981 with the RADAR conference (Oliver, 1981) and in 1983 with the book named "Social Work with Disabled People" (Oliver, 1983). Oliver's work has developed this new definition to be a method of studying disability and to be called The Social Model of Disability (Finkelstein, 2001a; Oliver, 2004; Thomas, 2004b).

According to the Social Model, the interaction of the individual body with an impairment and the obstacles in the social/built environment excludes disabled people from society and restricts their activities (Oliver, 1990; Finkelstein, 1990a; Albert, 2004; Thomas, 2004b; Siebers, 2008b; Shakespeare, 2010). The social model

of disability had a straightforward argument, was easy to describe, and thus effective (Shakespeare, 2010). The model has become internationally more popular as a socio-political movement on disability (Erkılıç, 2011), and in the last four decades, it has provided an essential perspective for disability studies, rights and policies. In 1994, WHO also complied with the understanding of the social model and changed the definition of disability according to this point of view (Burcu, 2020). The current definition, taking place on the WHO (n.d.) website, is as follows:

> […] Disability results from the interaction between individuals with a health condition such as cerebral palsy, down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support.

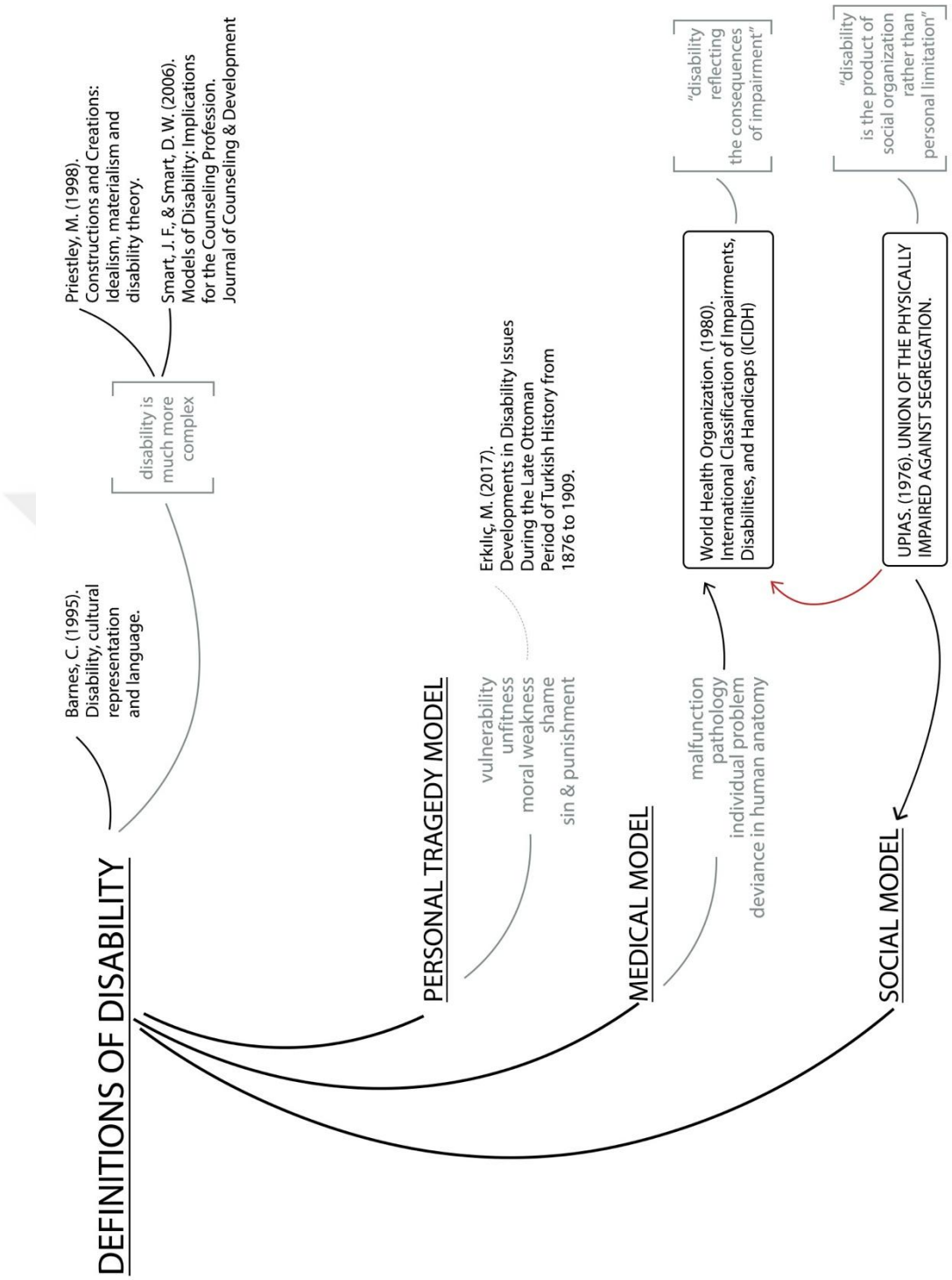


Figure 1.1 Map of the Models Defining Disability

The social model embraced the idea that failures in a social organization prevent equality of opportunities and effective participation of disabled people in society, inclusiveness, and thus make disability a particular form of social oppression (Oliver, 1990; UPIAS, 1976; Barnes, 1995; Thomas, 2004b; Smart & Smart, 2006). Social oppression can be experienced by being exposed to "material disadvantages, powerlessness and demeaning cultural stereotyping" (Barnes & Mercer, 2003, pp.40-41). The social model aims to fight this oppression and liberate disabled people. Tom Shakespeare (2010), a social scientist and bioethicist at the University of Cambridge, defined this liberation as having human rights like participating fully in society, living independently, undertaking productive work, and having complete control of their own lives. In other words, for the social model, the liberation of the disabled is not curing or cutting off the impairment but celebrating being different while having the right to be equal (Morris, 1991).

To provide those opportunities to disabled people, the social model argues the necessity to remove social and cultural barriers. After embracing the social model, WHO (2011) listed the disabling barriers as inadequate policies and standards, negative attitudes towards disability, lack of provision of services, problems with service delivery, inadequate funding, lack of data and evidence, lack of consultation and involvement, and lack of accessibility. To remove those barriers, several measures were taken at national and international levels.

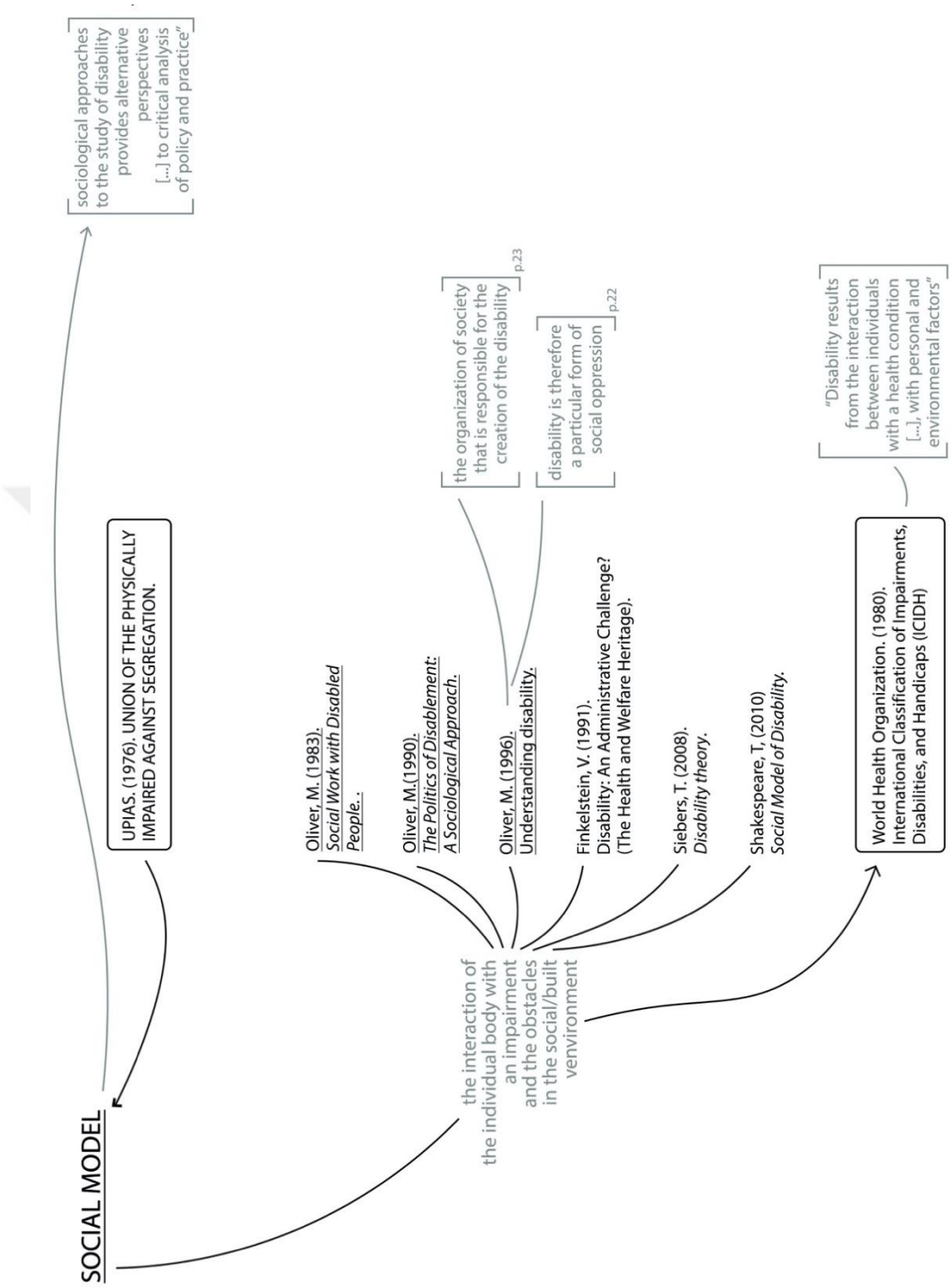


Figure 1.2 Map Illustrating the Background of the Social Model

1.1.2 Attempts to Remove Disabling Barriers

One of the precautions taken for the liberation of disabled people was that governments and disability rights advocates established policies and laws. Some of the legislative backgrounds of the liberation can be listed as the *American Disability Act (ADA, 1990)*, The *Disability Discrimination Act (DDA, 1995)*, the *Turkish Law about Disabled People (Engelliler Hakkında Kanun, 2005 & 2013)*, and the *United Nations Convention on the Rights of Persons with Disabilities (2006)*, which is also the first comprehensive human rights treaty of the twenty-first century. The purpose of the present convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

The fundamental aims of these new laws were to prohibit discrimination against disabled people and to ensure full participation by providing equal opportunities in every aspect of public life, such as education, public accommodation, telecommunication, and transportation (Story, Mueller, Mace, 1998). In each legislation, the difficulties in the built environment that disables people with impairments are mentioned under the code of accessibility.

These codes resulted in establishing a series of regulations and standards for the construction industry, which are designated to remove or minimize the negative effect of inaccessible environments on the life of disabled people. Those standards were defined by several institutions such as *ADA Standards, American National Standards Institute (ANSI), International Standards Organizations (ISO)*, and, in Turkey, by *Turkish Standards Institution (TSE).*

However, the legislative codes and regulations were criticized for providing misleading and unhelpful technical information. They are mostly viewed as add-on solutions, segregated accessibility features which have clinical impact, and thus considered as restrictions for creativity and aesthetics by architects (Story et al., 1998; Steinfeld & Tauke, 2002; Imrie, 2004; Heylighen et al., 2016; Bordas Eddy,

2017a). Moreover, when the standards are examined, it can be seen that there is a strong emphasis on people with a narrow range of specific disabilities (Knecht, 2004). Most of the standards concern physical barriers in the built environment which disables people with mobility impairments (Imrie, 2000). The reason for this emphasis can be that, as disability studies scholar Aimi Hamraie (2019) stated, accessibility has been used to refer exclusively for the barriers that people with visible impairments face, such as wheelchair users. As a result of this understanding, code compliance with minimal standards resulted in designs which respond to the needs of a narrow range of users with legible disabilities (Hamraie, 2016; 2017; see also Hall & Imrie, 1999). One other drawback of legislative codes was that the minimum criteria that were established by standards were interpreted as the maximum needed by the construction industry for the sake of being efficient (Imrie, 2000; Salmen, 2011), and this prevented designers from developing new creative solutions that may be more accessible (Steinfeld & Tauke, 2002). In addition, for many years, not all built environments have been required to comply with accessibility standards since they only covered certain building types; for instance, it was thought that private housing couldn't be required to be accessible (Mace, 1998). Furthermore, the empirical study of Rob Imrie (1997), a scholar who studies urban policy and disability, showed that few of the access officers who are in a position to affect local policies in the UK are people having disabilities. Imrie (1997; p.445) suggested that being developed and implemented by able-bodied people makes access policies a demonstration of the exclusion of disabled people and individualizing disability. In order to promote creative design beyond accessibility standards and to make a broader range of designed products and environments be used by the widest pool of diverse abilities, a new strategy is defined by scholars, the discourse of Universal Design (UD)[1] (Story, 1988; Sanford et al., 1988; Hamraie, 2016; 2017).

[1] Please see Appendix A

According to Molly Story, Jim Mueller, and Ron Mace (1988), the members of the group defining UD, removing disabling barriers demands an understanding of different abilities, preferences, and body typologies that were considered abnormal. The reason is that, according to UD, designing by considering the abilities of systematically excluded bodies is beneficial for much larger user groups, including the ones considered to be normal (Sanford et al., 1998; Bühler, 2001; Steinfeld & Tauke, 2002; Aragall; 2003; Miller et al., 2004; Ginnerup, 2009; Hamraie, 2013). For instance, it was seen that the buses designed considering people with wheelchairs in London benefited parents with a stroller, and the Big Button Phone, designed for partially sighted and older people, was preferred by many others (Miller et al., 2004). Another example is that the touch screen voting machine, designed by IDEO for Los Angeles County for the 2020 elections, was intended to be used by people with cerebral palsy but ended up being useful for many other voters (Thompson & Rothman, 2018). To define the needs of a larger population for the sake of practicing universal design, older people and people with disabilities are seen as two specific groups to research since both represent medicalized and stigmatized identities with diverse abilities (Hamraie, 2013).

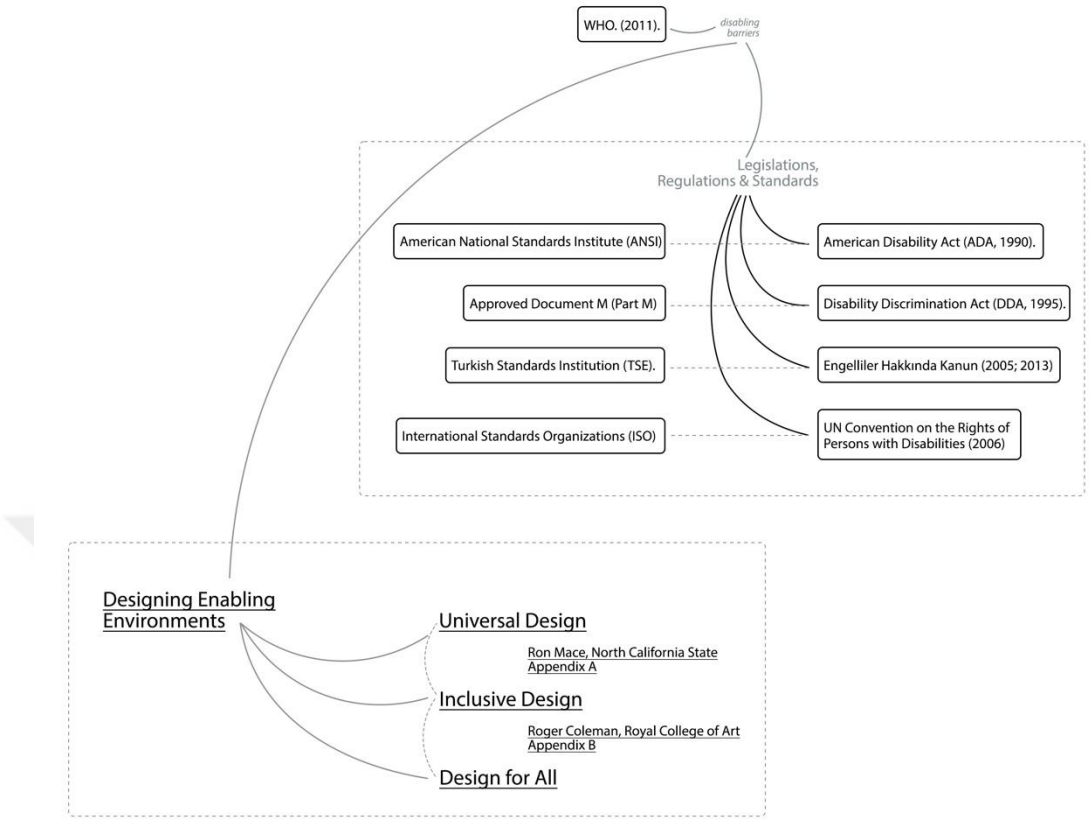


Figure 1.3 Map of the Attempts to Remove Barriers

To generate an understanding of human variability and complexity, designers may try to develop empathy (Lifchez, 1986; Murrow, 2001; Bordas Eddy, 2017a), may consult users, especially the ones with different body types, to learn more about their abilities or wishes (Ostroff, 1997; Murrow, 2001; Ringaert, 2001; Heylighen et al., 2016) or a variation of people who gained knowledge by their atypical bodily experiences may be encouraged to participate in design disciplines (Lifchez, 1986; De Graft Johnson et al., 2005; Vermeersch et al., 2012; Manley et al., 2011; Manley & De Graft-Johnson, 2013; Braitmayer, 2019) for the purpose of making design products more enabling. In all three, a strong emphasis appears to be on learning from the experiences of different users and the effective participation of different designers in the disciplines.

1.1.3 The Definition of the Problem and Limited Areas

It is not new in architectural discourse to focus on experience; Christian Norberg-Schulz (1996) defined *architecture* as the "concretization of existential space", the space which consists of relationships between humans and the environment. Those relations between body, space, experience, and knowledge can also be seen in the writings of philosophers. According to Merleau-Ponty (2017), the existence of space is related to the presence of the body. He says that analyzing their own body and its movement makes people understand the space. Likewise, Jale Erzen (2015) supports the idea that the body and environment form each other, and the body is the main factor that gives meaning to space (see also Crowther, 2009). She argues that bodily perception develops cognitive abilities and enriches people's subconscious. In a similar manner, Lefebvre (1974/2019) supports the idea that body and perception/production of space are related. Moreover, Pallasmaa (1996/2011) defined the body as a knowledge resource. He exemplified this by saying that just like a bird using its body to shape the nest, our bodies stand as guides for us to produce architecture. With that respect, it can be said that all bodies, able and disabled, do not communicate with the space in the same way; therefore, their concretization of experience would not be the same.

However, it can be said that the number of diverse bodies in architecture is limited (Lifchez, 1986; Murrow, 2001; Anthony, 2002). These homogeneous characteristics of the architectural profession may be one of the causes of the limitations in complying with universal design principles and the lack of priority given to the barrier-free design. Imrie (2003) relates this situation to the idea that most architects conceive user bodies by taking references from their bodies unless the user body is defined explicitly for the project (see also Davis & Lifchez, 1986; Keates & Clarkson, 2003). A parallel discussion takes place in the book named Üç Habitus, written by Jale Erzen. While examining the city in her book, Jale Erzen (2015, p.112) says that designers make decisions by considering themselves or people similar to them and argues that this situation reduces the city to a single dimension. Although

Erzen discusses this issue through culture and lifestyle, physical differences and disability experiences can be considered together with her perspective. She (2015, p.14) also claims, "Awareness is a skill that can only develop with a variety of perception and experience.". So, one can say that increasing the number of diverse bodies in the profession may result in raising awareness and sensitivity among architects (De Cauwer et al., 2009) and, thus, be effective in changing the conception of user bodies. As a result, this improvement may lessen the barriers in the built environment, make architects design according to UD philosophy, and enable disabled people to participate in society as "valued and contributing members", in Adrian (1997) 's words.

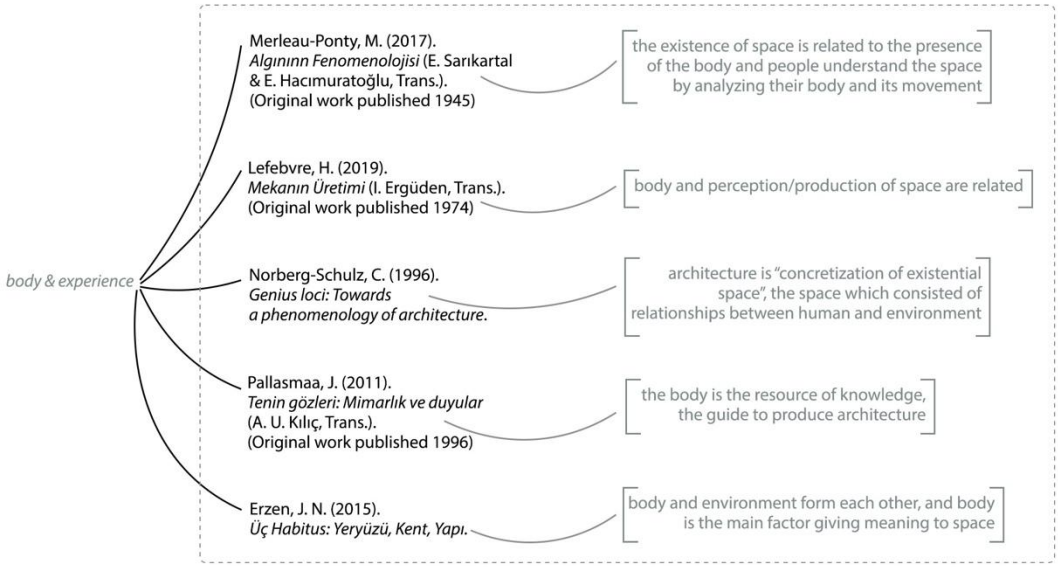


Figure 1.4 Map of the Discussions Related to Body & Experience

1.2 The Aim of the Study and Research Questions

In this thesis, my aim is trying to conduct analytical research on the possibility of involvement of people with the experience of disability in architecture, the barriers that disabled architects can face during architectural education and practice, and the possible level of contribution that disabled architects can make to architectural discourse by the new and extraordinary perspective of having disabilities, and the

negative effects of absence (or lack) of disabled architects on disability rights. To summarize, the research questions of this study are:

1. What are the reasons and goals for the idea that people with disabilities should participate in architecture?
2. What point of view should be used to make a shift in the architectural profession to achieve active participation of people with disabilities?
3. What contributions have been made by people with disabilities to the profession of architecture before?

1.3 Structure and Methodology of the Study

Those research questions will try to be answered in this thesis by an interdisciplinary analytical reading. Firstly, a literature review will be given in the sociology of disability to construct the background knowledge. In that part, the development and evolvement process of the Social Model, the establishment of supporting sociological approaches, the approaches that this study follows, the Social Constructive and Feminist Approaches to disability, and the problems and issues in the organization of society are discussed. In this section, parallel discussions in architectural discipline also take place.

Secondly, aligned with the sociological and conceptual background, a reading of the scholarship concerning disability and architecture was provided. Architectural methods, philosophies, and initial and recent studies were discussed in this part by focusing on Universal Design, and Participatory Design approaches. Moreover, this review includes an examination of the architects with different abilities and their contribution to the discourse of architecture. However, it should be noted that although the phrases of *the differently-abled* or *diverse abilities* refer to all, including older people, children, people with mental impairments, pregnant women, people with temporary impairments, etc., the examination of diversely abled architects' works were limited to the architects with physical impairments for this study.

Consequently, by drawing upon a series of literature, all of which address disability from a different perspective, it was aimed to shape the foundation of the idea that there is a necessity for equal participation of people with and without disabilities in society and the architectural profession. An information map was created to show the parallelisms, connections, and intermeshed structure of the discussions that took part in different disciplines and how they all came to the conclusion of supporting people with disabilities to have an active voice in the discipline of architecture. Producing this map aims to convey the statements of different discourses and their interrelations understandably.

1.4 Terminology

Since the disadvantageous position of people with impairments is reinforced by the disabling "official definitions and meanings," the critiques of language took a noticeable part in disability studies (Barnes & Mercer, 2003, p.17; e.g., Woodhouse et al., 1981). Although Tom Shakespeare (2006, pp.32-33) claimed that debates about language diverted the disability movement from its primary purpose, which is to change the social structure, it was said by other scholars that suggesting a social change necessitates building strong and persuasive language (Corker, 2000). Moreover, language is a powerful tool for establishing images and meanings and for affecting lives (Corbett, 1996). So, choosing the proper terminology is vital to prevent future misuse and avoid being part of "further legitimating disablist assumptions and discriminatory practices" (Barton, 1996, p.8). Thereupon, it may be practical to explain the language preferences of this study. The study's language is chosen according to the discussions put by disability theoreticians.

The definitions of 'disability' and 'impairment' generated by the social model were discussed before. This study follows the understanding of the social model. Briefly, the term "disability" is used to refer to a form of oppression, and “impairment" is used for a bodily condition. Further, it was refused to use the word "the disabled" to refer to the oppressed people since this wording implies the idea that all impaired

people are parts of a particular category in which there is not a "unique" characteristic of any individual (Brisenden, 1986, p.174). Poet and disability activist Simon Brisenden (1986, p.175) claimed that this label ideologically signifies that people with impairments are "non-people with non-abilities" who have no contribution to society.

With the same concerns, it was abstained from using "the disabled people" to refer to individuals with impairments since this phrase is pre-determining one's identity as if the person is only defined by his/her disability (Davis, 1995). This study only uses this phrase when it signifies the notion of being "disabled by society" (see also Shakespeare, 2006). When it is needed to refer to people with an individual deficit, the phrase "people with disabilities" was used to implicate that disability is an added quality to one's unique identity (Davis, 1995; Finkelstein, 2004; Shakespeare, 2006). Moreover, it was denied using the words "non-disabled" and "able-bodied" to refer to people who do not have impairments by some scholars whose idea was that the "able" body does not exist; it is only an abstract form. Instead, they proposed to use "people with capabilities" (Finkelstein, 2004, p.19) or "non-impaired" people (Hughes, 2004, p.66). However, it was observed that those phrases could not find a considerable place in mainstream disability studies, so this study uses the terms "non-disabled" and "able-bodied" to refer to people who are privileged and advantaged in the society.

And lastly, the phrases "differently-abled" and "people with different abilities" have been used in the literature (Davis, 1995). It was preferred to use "differently-abled architects" to refer to people who are the primary concern of this study. There are two main ideas behind this preference. Firstly, although feminist scholar Susan Wendell (1997, p.272) feels that these wordings had a condescending tone, she also stated that "the positive side of differently-abled is that it may remind that to be disabled in some respect is not to be disabled in all aspects.". Therefore, using these phrases would be beneficial to underline the architectural abilities of those architects. Secondly, the term "differently-abled" has an inclusive attitude and can refer to all

people. As the well-known specialist in disability studies, Lennard J. Davis (1995, p.xiii), explains, "ability includes but does not stigmatize disability.”.

It would be helpful to continue with the sociological and conceptual background to explain the philosophy behind this study and its language. The next chapter will be focusing on the underlying ideas of the study.

CHAPTER 2

SOCIOLOGICAL AND CONCEPTUAL BACKGROUND

As discussed above, with the perspective of the social model, the understanding of disability has changed, and the social model suggests that it is not the body or impairment that disables the individual, but the way society responds to that impairment (Oliver, 2004). Even though the potential of its understanding made the social model of disability popular among disabled people and scholars studying disability, the model's applicability and usefulness also became the topic of discussion and criticism (Oliver, 2004). The effect of the social model on the liberation of disabled people and gaining equal rights was seen as "incalculable" even by scholars with a critical view of the model (Crow, 1996). To shape the sociological background of this study, I would like to give place to discussions about the social model with its theory, contribution to studies, and the critics it faced.

To start, briefly mentioning the philosophy and acceptance of the social model can be beneficial. Mike Oliver (2004, para.10), the scholar who coined the term the social model, summarized the philosophy of the model in three articles which are (1) switching the focus from the impairment, resulting in functional limitation, to "disabling barriers, environments, cultures", (2) studying problems related to the disability with a holistic approach, instead of studying specific problems alone, and (3) not entirely rejecting the place of medical, rehabilitative, educational individually based interventions in the lives of disabled people.

Following that basis, sociologists put the idea that the way society is constructed "makes people with impairments incapable of functioning" at the center of the theory of disability (Finkelstein, 2001b, p.2). Therefore, in his article where Finkelstein (2001b) explained the early-stage discussions about the meaning of disability in UPIAS, he said that their interpretation of disability had focused on the idea of

changing society. That idea was stated as "adjustment" of society by Mike Oliver (1981, p.30). As a result, when the studies of the founders of the social model are examined, it can be said that carrying out this change has been one of the main ideas shaping the frame of mind of the social model.

Based on the same sources, the importance given to the role of disabled people in achieving this goal of social change can be interpreted as another main idea of the social model. The sociologists advocating the social model had constantly emphasized that people with disabilities should be the active agent of change. For instance, in the policy statement, where UPIAS (1976) opened the way for 'the Social Model' of disablement, it was rejected to be under the control of non-disabled 'experts', who, according to Colin Barnes (1995), a leading figure in the disability movement, had limited understanding of disability experience. Instead, it was suggested that disabled people are the experts in their struggle and should be in control when radical changes are necessary to overcome the oppression they face. In the same vein, one of the social model pioneers, Mike Oliver (1996b), claimed that people with disabilities could only be represented by organizations controlled by disabled people. The reason was that the social model accepts that failing about disability in all professions results from not involving disabled people in a meaningful way, except for passive objects (Oliver, 1990).

Similarly, another advocate of the social model, Vic Finkelstein (1987, cited Burcu, 2020, p.135), also believed that developments in disability rights could only be achieved with the efforts of disabled people (see also Finkelstein, 2001b). Finkelstein (1991) focused on the barriers constructing disability in his article named "Disability: An Administrative Challenge?" and claimed that there is no more effective way than working directly with disabled people to identify and remove those barriers. Furthermore, he underlined that removing disabling barriers is not related to "health and welfare" but an "environment" issue. With that understanding, he (1991, p.13) stated that

> [...] there would be a need for important new discipline developments in engineering and architecture. From this point of view, it seems perfectly appropriate for housing and adaptations officers working in local authorities to be disabled people and to be trained in the schools of architecture (or perhaps engineering).

More recently, Tom Shakespeare (2006, p.192-193) discussed the disabling barriers resulting from the "tradition of domination" in the relationship between carers/professionals and disabled people. He supported the idea that to change repressive practices and find more appropriate solutions while providing health and care services, the experiences and expertise of people with disabilities can be beneficial sources. For this purpose, Shakespeare proposed to include more disabled people in the health professions. He exemplified this idea by indicating that there are medical schools that benefit from tutors and lecturers with disabilities to educate students by arousing empathy.

After all these examples, it can be said that by generating the 'social model' of disability, disability rights advocates aimed to change both the definition of disability from medical to social and shift the actors of the social change, from non-disabled experts to experience owners themselves (Mason, 1992; Burcu, 2020). Nevertheless, being the powerful prevailing notion in Disability Movement made the social model be criticized and challenged (Oliver, 1996b; 2004) by the same actors that challenged society.

As the person to whom these criticisms were mainly directed, Mike Oliver (2004) categorized the problems argued to be present in the social model and put forward his answers to each of them. Oliver mentioned the critiques of not including the experience and the material reality of impairment, the model's inability to integrate disability with other oppressed identities, not involving representation and cultural meaning of disability in discussions and being incompetent to work as a social theory. Although Mike Oliver (2004) defended the opposite, the critique that the

social model denies the experience of a physically or intellectually impaired state of the body was extensively discussed and supported by scholars (e.g., Abberley, 1996; Crow, 1996; Hughes & Paterson, 1997; Schriempf, 2001; Hughes, 2004; Shakespeare, 2006), among other issues. This debate took a considerable part in disability studies (Hughes & Paterson, 1997) and resulted in new perspectives generated around the social model. To build the sociological foundation of this study, it would be helpful to take a brief look at those critiques and their consequences.

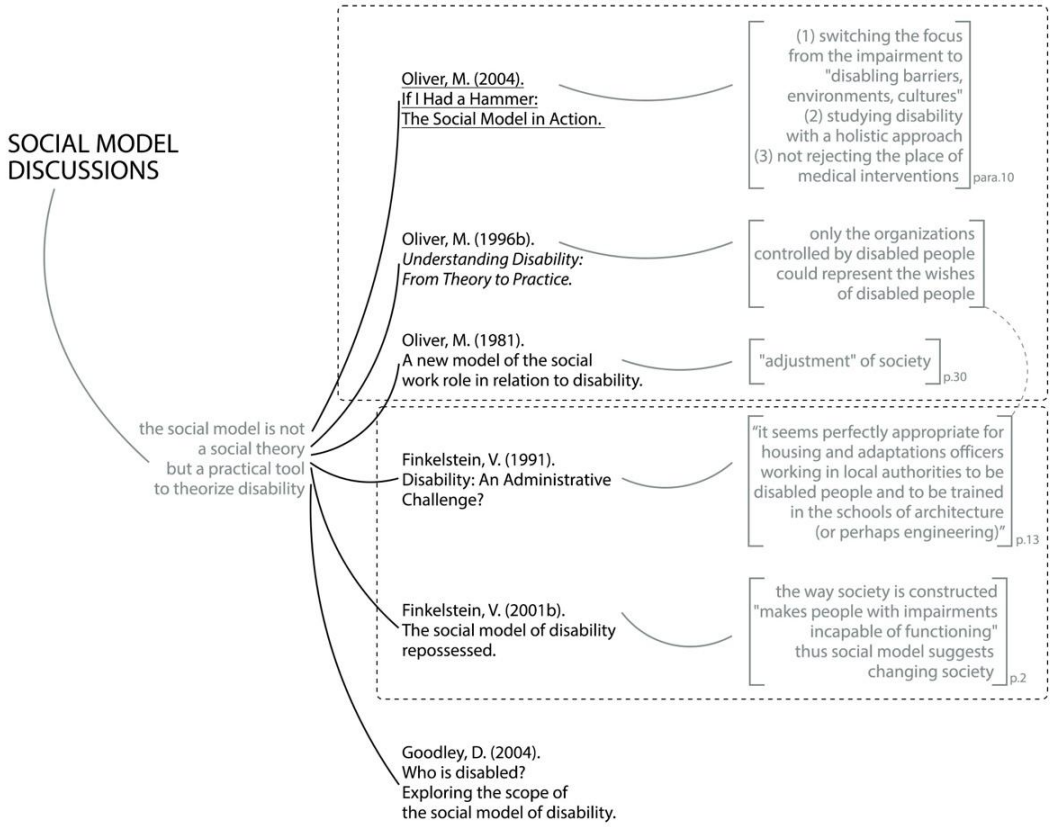


Figure 2.1 Map of the Ideas Defending Social Model

2.1 The Internal Debates: "Rectified" Social Model

As discussed before, the social model's strength was the outcome of being based on a clear agenda of shifting the focus from the body's functional abilities to society's disabling barriers (Shakespeare, 2006; 2010). Nonetheless, according to a group of

scholars, "the strength and simplicity of the social model have created as many problems as it solved." (Shakespeare, 2006, p.31). They discussed that there are two main problems present in the social model understanding.

Firstly, the model's standpoint of the disability/impairment distinction was seen as verging on saying that bodily condition has no role in disability experience (Morris, 1991; Crow, 1996; Hughes & Paterson, 1997; Barnes & Mercer, 2003; Shakespeare, 2010). It was stated that impairment and disability are two different but related subjects (Schriempf, 2001), whose boundaries are not always clear (Hughes & Paterson, 1997; Barnes & Mercer, 2003; Shakespeare, 2006). However, the social model ignores and marginalizes impairment and the body, which constitutes a significant part of all humans' fundamental beings (Hughes, 2004), and leaves it to the scope of medicine (Hughes & Paterson, 1997). Secondly, they argued that the social model's proposal of social change was not an optimum solution for all the problems associated with disability. The reason for this was shown as the removal of barriers would help people with disabilities to cope with their oppressed position in society, but non-oppressive restrictions like the material reality of having an impairment and the accompanying health problems would not change with the disappearance of the barriers (Morris, 1992; Abberley, 1996; Crow, 1996; Shakespeare, 2006). Likewise, the Liberation Network of People with Disabilities (Woodhouse et al., 1981, p.19) indicated this situation in their policy by stating that, unlike other oppressed identities, people with disabilities have an "inherently distressing" experience, such as physical pain and fatigue, which cannot be eliminated by social change. After all, these debates were seen as the "richness" of disability studies (Thomas, 2004a, p.21) and was said to be “needed” to strengthen disability theory (Shakespeare & Watson, 1997, p.293).

This viewpoint embraced the idea that although social and medical models were constructed as dichotomous conceptions of disability (Edwards & Imrie, 2003; Thomas, 2004b; Shakespeare, 2006; WHO, 2011), theories and experiences of disability are too complex to discuss under these two separate models (Priestley, 1998). Still, sociologists have not argued that the social model should be abandoned.

Shakespeare (2006, p.30) clearly stated that the social model is "crucial" for the Disability Movement (see also Morris, 1991), and removing the environmental and social barriers, as the social model supported, is the leading concern of the Movement since those are the main barriers disabling people. It was believed that leaving the social model for the sake of involving impairment would result in a turn back to medicalization and individualization of disability (Finkelstein, 1996; Shakespeare & Watson, 1997; Thomas, 2004a). This is why sociologists advocated that those discussions should be internal in the social model, and the model should continue to control the study of disability as a decisive organizing factor (Thomas, 2004b) in a new perspective so that it can include the full complexity of disability phenomena and their relations (Crow, 1996; Hughes, 2004). They proposed that the model and the definition of disability should be expanded (Hughes & Paterson, 1997, p.326), "rediscovered and reasserted" (Thomas, 2004b, p.580), and "revised" (Shakespeare, 2006, p.34) or “rectified” (Shakespeare, 1993, p.257).

The existing critiques were also forming the method to be used to expand the social model. After looking at those critiques, it can be said that the common ground of those discussions against the social model was the lack of space given to various relationships disability had with other subject matters, such as body, pain, race, gender, representation, etc. Questioning existing forms of relations was seen as a part of studying disability as a sociological subject (Barton, 1996). The scholars supporting the idea of rectifying the social model had put emphasis on those relationships and claimed that sociologically progressed disability studies require alternative theories to critically analyze those relationships (Barton, 1998; Thomas, 2004b). It is possible to say that this search for new approaches is also compatible with the ideas that social model advocates, who are also against the concept of and the use of the term rectify (Finkelstein, 1996; 2001b), have offered since the very beginning to respond to criticism. Oliver (1996b; 2004) and scholars who agreed with him, Finkelstein (2001b; 2004), and Goodley (2004), had said that the social model is not a social theory defining disability but a practical tool that can be used to theorize disability.

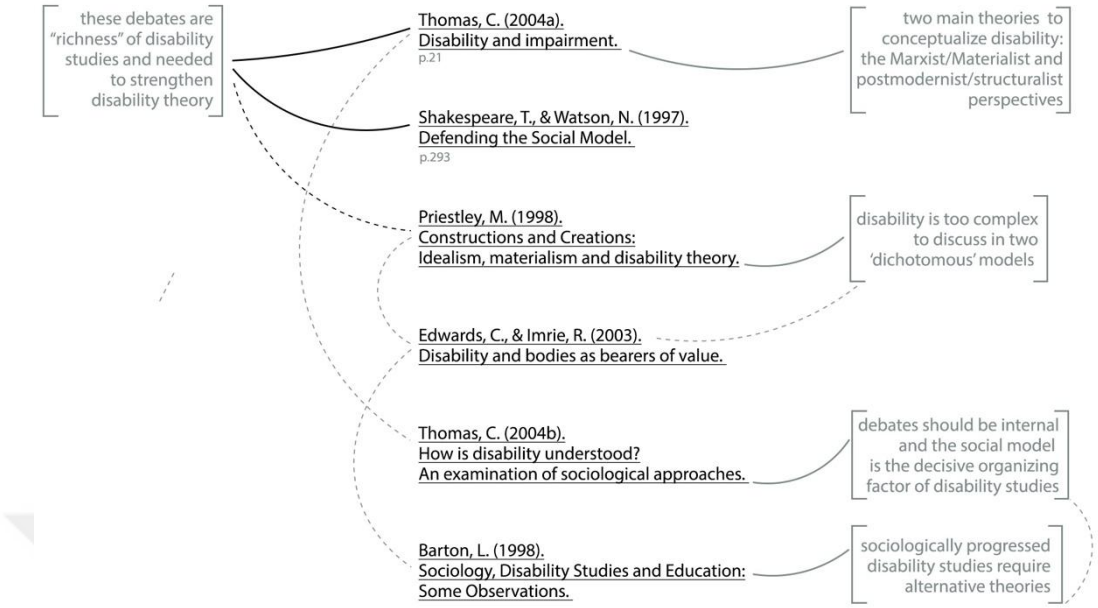


Figure 2.2 Map of Illustrating Scholars' Comments on the Internal Debates

Len Barton (1998) suggested that adopting a sociological theory could build alternative perspectives for disability studies. According to Carol Thomas (2004a, p. 23), there are two main theories that contribute to the conceptualization of disability: the Marxist/Materialist and postmodernist/structuralist perspectives. She had said that other theoretical axes could be formed as variations of those two. Prof.Dr.Esra Burcu Sağlam, who has contributed significantly to the paradigm shift in academic studies on disability, sociology, and the theory of disability and methodology of disability studies in Turkey from the medical model to the social model (see also Burcu, 2015), summarized the approaches to disability taken place in the literature in her book. By classifying definitions and discussions of approaches to disability under six titles, Burcu (2020) explained how each makes the social model evolve and improve. Those approaches offer eclectic discourses on disability under certain relations (see also Barton, 1998), which also have caused critiques of the social model in the first space, and sometimes interlaces with another. The approaches compiled and summarized by Burcu can be given as follows:

1. The Structural-Functionalist Approach, studying disability under the relations of value system in industrial society and the disadvantageous role of disabled people (Topliss, 1982; Oliver, 1990; Abberley, 1998)
2. The Conflict Theory Approach, studying the unjust distribution of resources to different social groups as a result of the power relations that emerged with the capitalist system (Oliver, 1990; Engels, 1845/1987; Doyal, 1994)
3. The Symbolic Interactionist Approach, studying the means of categorizing people and the stigmatization of the discrepancies in the network of interactions of a society (Ritzer, 1990; Goffman, 1963/2009)
4. The Post-Structuralist and Postmodernist Approach, studying the formation of social order, marginalization, and labeling of people by the effect of language and cultural values, images, and codes created by language in the dominant discourse (Davis, 1995; Corbett, 1996; Corker, 2000)
5. The Social Constructive Approach, studying the construction of able and disabled bodies by the practices of the society (Barnes, 1995; Turner & Louis, 1996; Siebers, 2001)
6. The Feminist Approach, studying the relationship between oppression of disability and gender, body, cultural representation of the body (Morris, 1991; Wendell, 1997; Schriemph, 2001)

Given the significance of Burcu's studies on the development of the sociology of disability in Turkey, it is reasoned to follow her classification of approaches for this study. Although all these approaches were taken into account for this thesis, the sociological background of this study is mainly shaped by two of those approaches, which are the ones making mention of the relationship between disability and architecture. These approaches are studied in the subsequent parts to clarify the foundation of the aim of the study and its research questions.

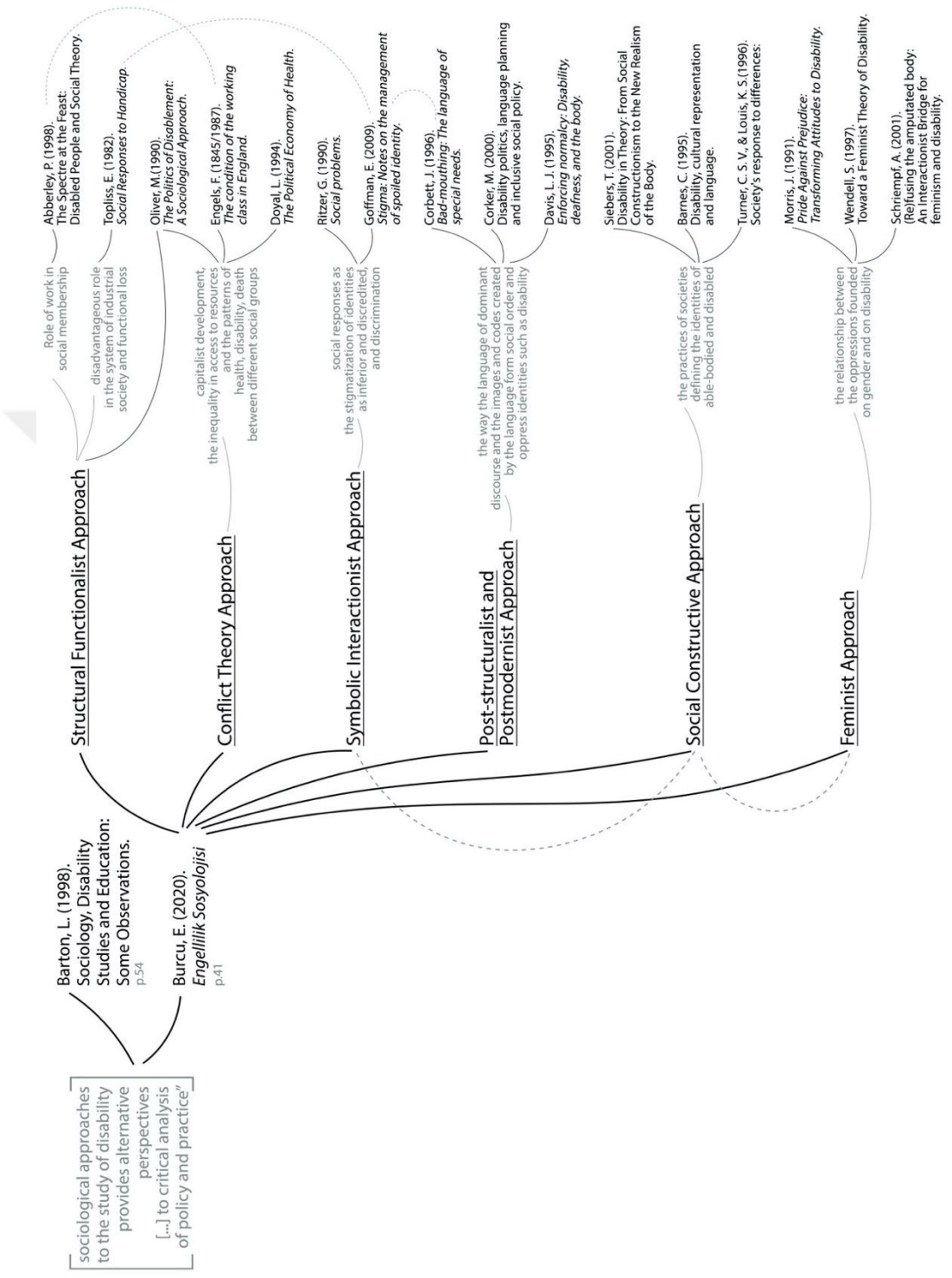


Figure 2.3 Map of the Sociological Approaches to Disability

2.1.1 The Social Constructive Approach

Mike Oliver (1996a) claimed that sociologists starting to consider disability as a topic of discussion is a result of being affected by Michel Foucault's interest in the body. For this reason, it was found beneficial to examine Foucault's philosophy and its relations to disability for this study. According to Foucault (1966/2005)'s examinations in the Chinese Encyclopedia, in which the taxonomy of animals was described, there weren't any categories for the animals that were seen as dangerous or hideous by people. The idea was that by not mentioning the atypical ones in the taxonomy, their existence was ignored and prevented for the purpose of creating an ideal utopia. While describing the relationships between three fundamental problematics about knowledge, power, and ethics, Foucault (1994/2019) also describes a similar act of exclusion of various groups from the societies. According to Foucault (1994/2019), different practices in the organization of society (such as prison, hospital, education, discourse, and regulation) resulted in creating a human model and marginalizing others, like the insane and the criminal. He argued that the exclusion of atypical ones is an effect of the normative system, and by tracing its formation, a critical practice for exceeding the limits of the system can be found (Keskin, 2019).

Sociologists also discussed that how societies react to deviations from a specific social norm creates the dichotomy between the accepted and the marginalized ones (Turner & Louis, 1996). Therefore, a new concern in disability studies has emerged that the identities of the able-bodied and disabled are also defined by the practices of societies (Davis & Linton, 1995; Turner & Louis, 1996; Adrian, 1997; Siebers, 2001; Burcu, 2020). This power of society in defining identities was described by Siebers (2001; p.737), who claimed that "[…] all bodies are socially constructed, and social attitudes and institutions determine far greater than the biological fact the representation of the body's reality.". In other words, social constructionism supports the idea that by the influence of dominant beliefs, attitudes, and customs of a society,

people victimize, oppress, and discriminate against the unideal, unlike, unknown or anomalous ones (Barnes, 1995; Stone, 1995; Charlton, 1998; Siebers, 2001).

However, the social constructive approach does not necessarily relate the creation of disability by society to the bodily condition (Crow, 1996). According to this approach, society also has the power to construct abnormality by systematic exclusion (Foucault, 1994/2019; Barnes, 1995). In other words, a disabled identity can be constructed by society's acts even in the absence of impairment (Davis & Linton, 1995). In the same vein, while defining disability, American Disabilities Act (2021) stated that people without any impairment are also regarded as disabled if they are treated as one by others. For example, people with a scar on their faces are also exposed to discriminative acts in society (Davis & Linton, 1995) and thus regarded as a member of the disabled community.

After accepting that defining disability is a subject of social discussions (Bérubé, 1998), the supporters of the social constructive approach tried to identify practices constructing disability. Use of discriminative language (Barnes, 1995; Barton, 1998), not getting a proper education needed for adult life because of the special education system (Oliver & Barnes, 2010), not being able to live independently because of limited job opportunities in capitalist societies (Oliver, 1990), being forced to use specialized design elements, devices, and structures for the sake of accessibility in the built environment (Erkılıç, 2010), and other practices and customs derived from dominant able-bodied lifestyles (Finkelstein, 1990a) in society prevent people with impairments from participating to society as equal members. This situation results in not having a life like so-called 'normal' people and thus empower the abnormal appearance of disability. Foucault (1994/2019) named these practices as 'dispositives' and claimed that by manipulating the power relations, dispositives make both society and the individual obey and believe in those given identities (see also Burcu, 2006).

The given list of dispositives can legitimize the acceptance of the social constructive approach that impairment is not the cause of the disability but a possible precondition

of oppression. Indeed, Liz Crow (1996, A Renewed Social Model of Disability, para.10) stated that "disability can dramatically ease or worsen with changes to an individual's environment or activities even when their particular impairment is static". Many examples of how societies' customs and power relations construct disabilities separately from impairment can also be found in sociologists' writings. One of the examples was given by Vic Finkelstein, who explained the construction and reinforcement of disabilities by society's understanding of disability by giving place to his own experiences. In his article, Conductive Education: A Tale of Two Cities, Finkelstein (1990b) compared how disabled he was in Budapest and New York. He said that in Budapest, where the medical model understanding was dominant and using a wheelchair was seen as an abnormality, the disabled people tried to be as *normal* as possible, but the city was inaccessible, and his body was not welcomed. So, the longer he stayed in Budapest, the more he felt "disabled, anxious, vulnerable, and dependent". On the contrary, while staying in NY, which is not an all-accessible city but has wheelchair-friendly busses and modern, accessible public buildings to provide equality, he felt less disabled, increasingly confident, and less isolated. The reason was that in NY, he was enabled to participate in society thanks to accessible public transportation and to meet with his peers in the streets. In other words, he had the same body in both cities, but people's view of disability constructed both the cities as accessible/inaccessible and bodies as abled/disabled.

In his book, The Politics of Disablement: A Sociological Approach, Mike Oliver (1990) exemplified the cultural production of disability by discussing anthropological studies of disability. One of the studies he mentioned was about Martha's Vineyard Island, where a high proportion of the population had hearing impairment, conducted by Nora Ellen Groce, the Director of the Disability Research Centre at University College London. Groce (1980, 1985), while searching for the roots of the impairment in the island's population, tried to observe the effects of this situation on the society's form of life. She found out that Vineyarders generated a traditional sign language that they used in all life activities whether there is someone with impairment or not. Since this is a "bilingual speech community", as Groce

defined them, people with hearing impairment participated freely in the society and were not seen as unusual. Oliver (1990) commented on this study by saying that this shows how our societies constructed people with hearing impairment as disabled identities. He claimed that, in reality, the disability is not the result of the individual having an impairment and being unable to communicate but the result of society failing to learn how to communicate with those people.

In their article, in which they tried to explain different models of defining disability, Julie Smart & David Smart (2006) gave a striking example of how society decides who is disabled or not and constructs disabilities. As presented in the article, during World War II, to respond needs of the U.S. Army, many people who had been kept in institutions for being mentally disabled were taken to the military and fought in the war. After the war, regardless of how good soldiers they were, those people were retaken to the institutions and excluded from the society they fought for since military forces did not need them anymore. A similar situation was seen in civilian life during the World Wars. As cited by Oliver (1996a), before wars, disabled people could not participate in the workforce because the aim was to maximize profit and because people with impairments' identity was constructed as incompatible with this goal. During the wars, the industry's objective changed and focused on ensuring the continuity of production. This situation resulted in people with impairments being employed as laborers and even as managers. Although those people showed real success, after wars, they were dismissed and removed from the economy once again. Oliver (1996a, p.34) commented on this situation by stating that "disabled people are excluded from the workforce not because of their personal or functional limitations but because of the way in which work is organized in the capitalist economy.”.

That is to say, although the impairments or the individuals did not change, the society and power relations constructed, deconstructed, and reconstructed the disabled identities according to their own gain. Constructing disability without impairment has been discussed at the beginning of this chapter. These examples prove that social construction also covers the situations the other way round, which is for society, "[...]

the presence of an impairment does not mean automatic transfer to the status of a disabled person." (Barnes & Mercer, 2003, p.66).

The fact that society has so much power over the lives of a particular group of people, practices of discrimination, and the exclusion of specific identities are against the legally protected rights of people. For example, in the UN Convention (2006), the dissociation of any kind was considered as violating fundamental rights and inherent dignity, and a similar article takes place in each policy on human and disability rights. This is why in the socially constructive approach, disability is viewed as a socio-political issue (Albert, 2004) and thus as a public concern (Smart & Smart, 2006). This socio-political point of view and a strong emphasis on human and civil rights resulted in generating a sub-model named the human rights approach, which offers a societal transformation and changes the status of disabled people from stigmatized objects to subjects of their own lives (Albert, 2004).

As mentioned above, Foucault (1994/2019) also claimed that the normative system can be changed, and the identities it produces can be transformed. Sociologists also tried to define the needed societal transformation. For instance, Smart & Smart (2006), who are also pioneers of socio-political and human rights approaches, provided the prescription of deconstruction by claiming that disability is not inevitable and can be deconstructed by society. Their prescriptions consisted of three aspects, which are:

> […] (a) People with disabilities must define disability; (b) people with disabilities must refuse to allow "experts" or "professionals" to define the disability, determine the outcomes of their lives, or judge the quality of their lives; and (c) people with disabilities refuse the "disabled role" of deviance and pathology. (p. 34)

This study follows the acceptance of the social model with the perspective of the social-constructive and the human rights-based approaches. With this viewpoint, the

traces of how the disability is constructed by and in the architectural profession were searched. As given above, sociologists supported changing the role of the disabled in society to transform the constructed meaning of disability. Studying ways of a similar change in the role of disabled people from passive objects of design to actors of architecture constitutes the main scope of the rest of this study. However, this kind of research and its understanding is also founded on the theories of the feminist approach to disability. This is why the feminist approach will be discussed briefly in the following part.

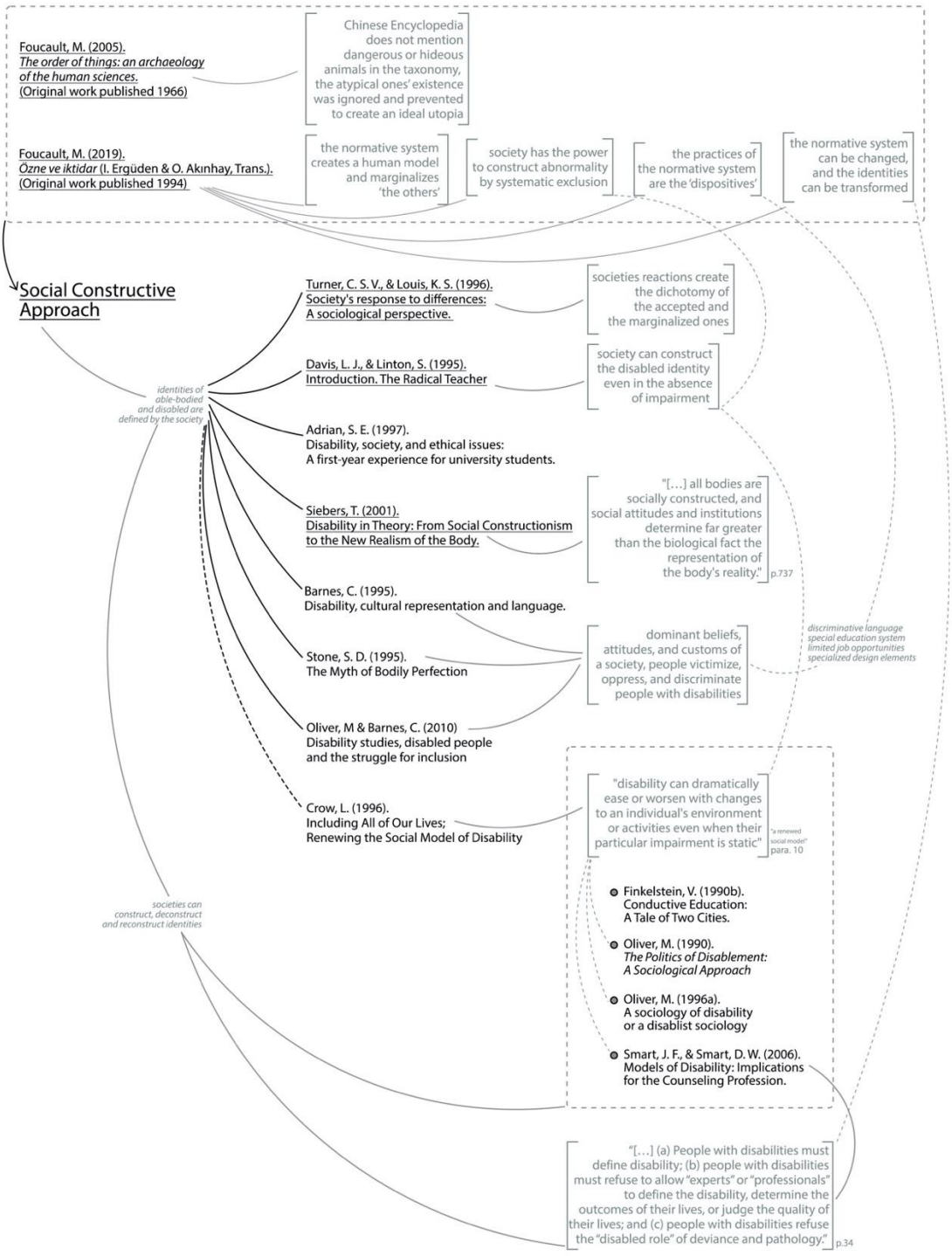


Figure 2.4 Map Illustrating the Social Constructive Approach to Disability

2.1.2 The Feminist Approach

Although approaches to disability have different viewpoints, there are also intersections between the theories they produced. Like the social-constructive approach, the feminist approach to disability adopts the idea that the identity of the disabled is socially constructed (Burcu, 2020), but it also creates a new perspective of interpreting the interrelationship between different oppressed identities.

The foundation of the feminist approach to disability started with scholars' critiques of feminism and the social model. They claimed that the disability theorists and feminists were ignoring the experiences and concerns of disabled women, which differ from non-disabled women and disabled men (Fine & Asch, 1981; Morris, 1991; 1992; 1993; Begum, 1992; Schriempf, 2001; Garland-Thomson, 2002; Ghai, 2002). According to feminist scholars, there was a need to combine feminism and disability studies to create a new perspective in which the intersecting oppressions of being female and disabled can be studied and clarified (Schriempf, 2001). Through this new perspective, it was believed that the knowledge and experience of disabled people could amplify feminism (Wendell, 1997; Garland-Thomson, 2002), while feminist theory deepens disability studies with its methods and insights (Garland-Thomson, 2002).

The advocators of this new paradigm put the relationship between body and identity at the center of their studies. The feminist studies focused on how the culture, the representational systems, the politics of appearance, and the social interpretations of bodily differences attribute meanings to bodies and construct oppressed identities (Garland-Thomson, 2002). Those studies resulted in feminist theorists creating an analogy between the formation of gender and disability and claiming that disability is also a socially constructed narrative of biological reality like gender (Wendell, 1997; Schriempf, 2001; Garland-Thomson, 2002). In this theory, society categorizes bodies founded on biology with a norm of the normal body, a male, healthy, able body, in mind. And thus, it devalues those that do not conform to cultural standards

by classifying them as worthless, incapable (Garland-Thomson, 2002), less than human and incomplete (Morris, 1991), and inferior in many other aspects.

Scholars studying disability in the feminist context defined the terms of impairment and disability with this new paradigm. Rosemarie Garland-Thomson, (2002), a professor of English at Emory University focusing on disability studies and feminist theory, interpreted disability as an ideological, cultural system of stigmatizing bodies and differentiated disability from impairment. With this understanding, she defined the system of disability in four aspects:

> [...] first, it is a system for interpreting and disciplining bodily variations; second, it is a relationship between bodies and their environments; third, it is a set of practices that produce both the able-bodied and the disabled; fourth, it is a way of describing the inherent instability of the embodied self. (p.5)

Alexa Schriempf (2001), a scholar working on philosophy and women studies at Penn State University, followed the new feminist theory of disability, which she named "the interactionist model". Under this model, she also defined disability and impairment, but unlike Garland-Thomson, she did not separate those two terms entirely from each other. She supported that impairment is not only a material reality about the body and disability is not only related to society. She claimed that both terms result from classifying bodies and continued by saying that:

> Disability and impairment are both always about bodies in social situations and thus always about the material and social conditions of not just one's body and its abilities but also of one's environment. (p.70)

In both interpretations of the feminist approach to disability, the common idea is the place of the body in defining disability identity, as said above. In that ableist and patriarchal social order formed on the exclusion of different bodies, the female body

is more discriminated against and judged than the male body (Hanna & Rogovsky, 1991; Wendell, 1997). Thus, it is reasonable to think that the experience of female disabled bodies is different from male disabled bodies (Fine & Asch, 1981). With this perspective, scholars have tried to explore the experience of women with disabilities by studying the hypothesis of double disadvantage throughout the years. Those studies focused on the multiple oppression women faced concerning various notions such as coping strategies developed by women with disabilities against the experience of double discrimination (Lonsdale, 1990), the norm of the ideal female body and self-image (Odette, 1994), spouse and marriage (Burcu et al., 2006), risk statuses and poverty (Lindsey, 2015), exclusion from gender roles (Duman & Doğanay, 2017), prejudice and difficulties in making reproductive decisions (Huang et al., 2020), etc.

However, while accepting that women with disabilities are exposed to different acts of discrimination than other groups, the advocators of the new paradigm objected to studying the female experience as a double disadvantage under the feminist approach by giving two main reasons. Firstly, they claimed that the double disadvantaged body reduces the individual from being a human to being the sum of disability and femininity (Schriempf, 2001). Those scholars supported that the experience of oppression based on gender and disability is shaped in a complex relationship to understand with this additive perspective. They suggested understanding that relationship as an interwoven, intermeshed one (Morris, 1993; Schriempf, 2001; Garland-Thomson, 2002). Moreover, the scope of that intermeshed experience is not limited to women with disabilities but covers all oppressed identities, including men (Garland-Thomson, 2002). Secondly, Jenny Morris (1992; 1993, p.63), a feminist writer/researcher with a disability, argued that focusing on the double disadvantageous position of women with disabilities reinforces women's role as the "passive victims of oppression". Being affected by Morris, another feminist researcher Alessandra Iantaffi (2005, p.177), named the unique experience of women with disabilities as "layered" to diminish the pathological effect of the terms "double" and "multiple". With this understanding, Morris (1993, p.66) invited feminist

researchers to work to empower people with disabilities instead of drawing attention to the disadvantages and continued by saying that:

> [...] nondisabled feminists must also ask themselves where are the disabled researchers? students? academics? If they are truly to be allies, we need them to recognize and challenge both direct and indirect discrimination. Unfortunately, most nondisabled people don't even recognize the way that discrimination against disabled people operates within their workplace. Why do feminist academics put up with the way that most academic institutions fail to comply with the Disabled Persons (Employment) Act 1944 which requires them to employ a minimum of 3 per cent registered disabled people. Getting disabled people into the positions where we play a full role in carrying out research and disseminating it is as important for disabled people as the same process was and is for women.

Morris (1991) is also one of the advocates of the idea that people with disabilities are the ones who know their own problems best, and they should take a controlling role while producing solutions to these problems. For example, she emphasized the difference between the disability rights organizations "consisting of" people with disabilities and organizations "for" people with disabilities. Those reformer theories brought by the feminist approach and mainly Morris' vigorous discussion on the empowerment of disabled people have been focal points in this study. After discussing the feminist and social constructivist approach to disability teachings, which puts the body at the center of their research, it would be beneficial to research the bodies constructed by the architectural discourse. The rest of this chapter will discuss the representation of bodies in architecture and the causes and consequences of this construction process.

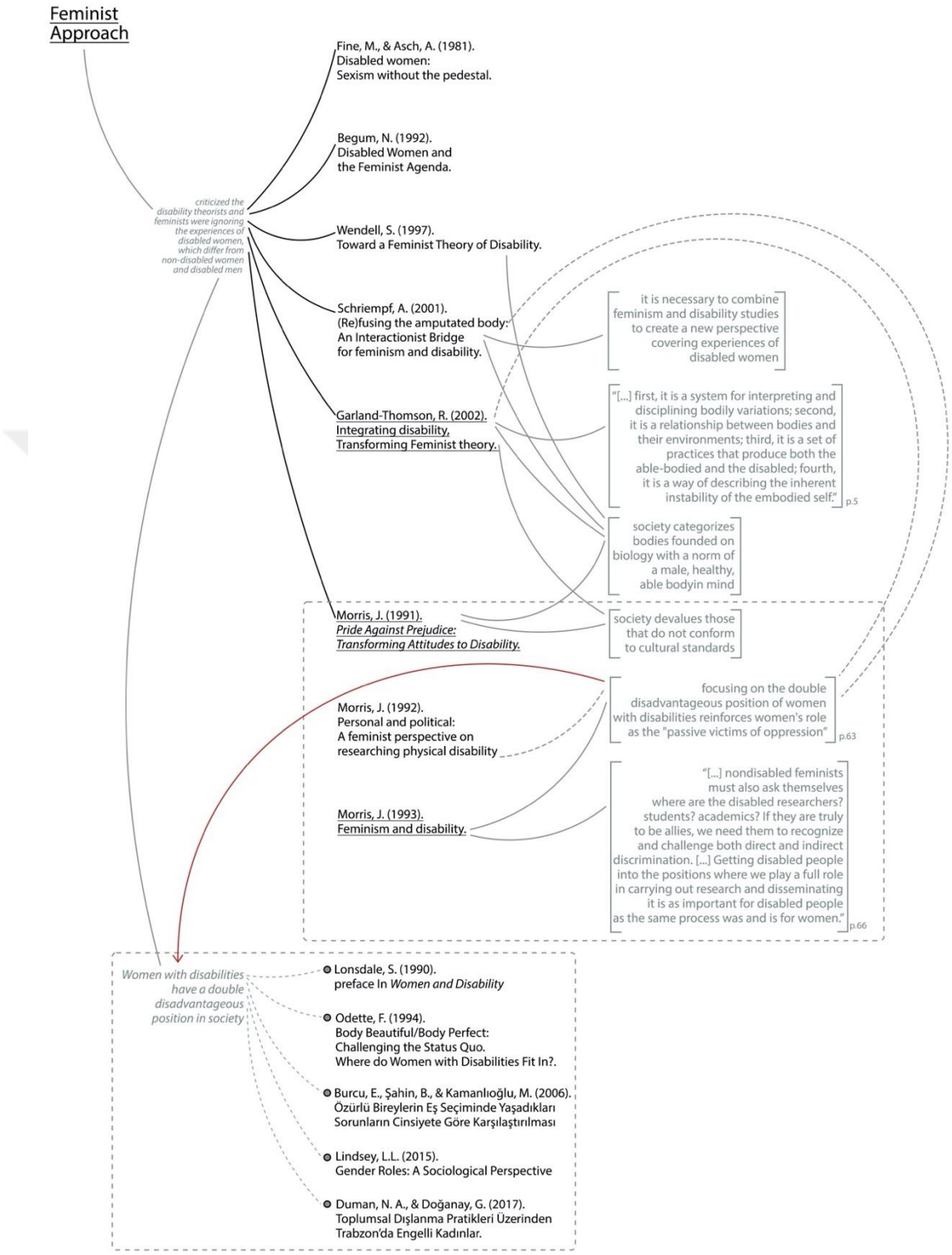


Figure 2.5 Map Showing the Discussions of the Feminist Approach to Disability

2.2 The Bodies Constructed in Architecture

As given above, the marginalized identities were studied by Foucault under the relationships of power. In the book named Discipline and Punish: The Birth of Prison, Foucault (1975/2019) also examined the effect of power on the body by claiming that after the classical period body became the object of those power relations. The economical use of the body, both as the producer and consumer, made it be tamed, manipulated, and changed to be more compatible. Foucault describes this situation as the creation of docile bodies as the products of the disciplines in the political system. Similarly, in the discipline of architecture, it can be observed that the human body has been the target of manipulations over time. As Beatrix Colomina (1992) claimed, architecture is a system of representations in which the body is a political construct. So, it can be reasonable to examine the architectural representations of the human body used in the profession to understand how the body is constructed and tamed by architecture.

In Vitruvius' *De Architectura,* a mathematical system of proportions was generated by references to the dimensions of the idealized human body (Vitruvius, ca. 30–15 BC/2017). Since this system was seen as the key to ideal perfection, an analogy based on the proportions of the ideal human body was created for the design of architectural and artistic products, especially religious ones. (Vitruvius, ca. 30–15 BC/2017; Agrest, 1988; Sennett, 1996/2018; Vidler, 1994; Zöllner, 2014). These understandings had kept their strength in architecture, and in the Renaissance period, architects reproduced the human body and theories of proportion in a similar way to Vitruvius' (Agrest, 1988; Vidler, 1994; Hosey, 2001; Rasmussen, 1959/2013). The drawings of Albrecht Dürer and Sebastian Serlio and Leonardo Da Vinci's *Vitruvian Man* are important examples of understanding the body in the Renaissance (Neufert & Neufert, 2012; Sennett, 1996/2018). By getting inspired by those drawings, architects designed cities with the system of proportion generated for the human body (Sennett, 1996/2018). The body, which was put at the center of architecture since antiquity, was considered as the embodiment of God (Imrie, 2003), who was

perfect in shape (Stone, 1995) so that it was represented as perfectly balanced, symmetrical, functioning, and strong man (Vidler, 1994).

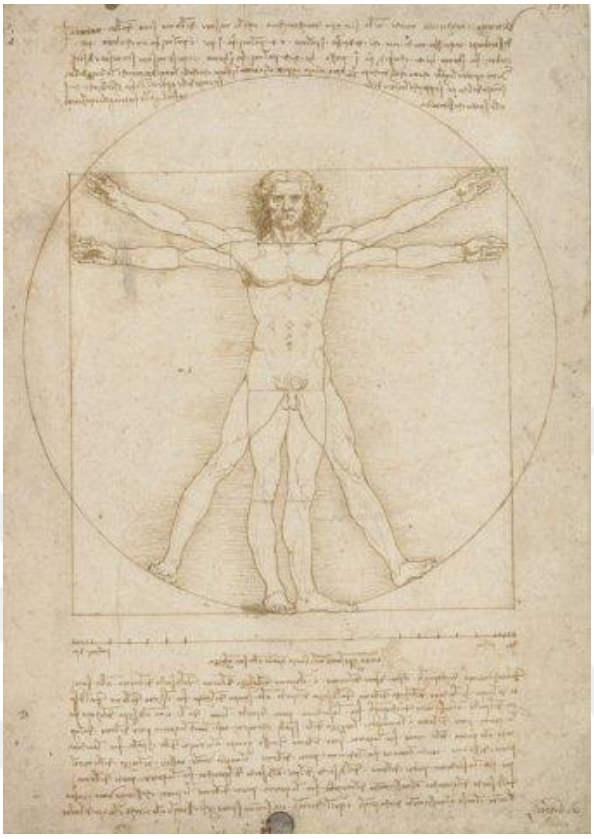


Figure 2.6 Leonardo Da Vinci's Study of the Proportions of the Human Body, the Vitruvian Man. (Gallerie Dell'Accademia di Venezia, n.d.). *Used Under Creative Commons BY-NC-ND License*

It can be said that the Vitruvian understanding had been criticized and lost power in 18th-century architecture (Vidler, 1994). However, after the effect of industrialization and mass production; standardization has been seen as a necessity for modernism (Rasmussen, 1959/2013; Beşlioğlu, 2020), and modernist architects attempted to standardize the human body by internalizing anthropomorphic proportions of classicism (Vidler, 1994; Rasmussen, 1959/2013; Zöllner, 2014). Probably the best-known example of those attempts is Le Corbusier (2004)'s *the Modulor*. Even though Le Corbusier was considered as the pioneer of modernism and logical design, the effect of Vitruvius' system of proportion and Reinassence's

understanding of the ideal body can be observed in the Modulor (Rasmussen, 1959/2013; Hosey, 2001). For instance, while trying to create a standard man, Le Corbusier strictly used the golden section (Corbusier, 2004) as Vitruvius did. Furthermore, to make Modulor more compatible with the golden section, he manipulated the body and changed the height of the Modulor from 175 cm to 183 cm (Rasmussen, 1959/2013; Zöllner, 2014).

In the 20th century, another attempt to standardize the human body was made by Neufert (1980). In the first editions of the book named *Architect's data*, although Neufert mentioned that there is a wide range of bodies, he supported the idea that the use of average human dimensions as standard criteria is necessary (Neufert, 1980). For this purpose, he designed a representation for the average body and a special modular system, that was called *Octameter*. However, similar to Le Corbusier, Neufert also manipulated the human body to make it more compatible with the module of Octameter and changed the height of shoulders from 143 cm to 150 cm while keeping the total height 175 cm (Zöllner, 2014). In the later editions of *Architect's data* (Neufert & Neufert, 2012), the dimensions for accessibility were mentioned in a more detailed way; even so, the standardization of the ideal human body with the golden section continued to take place.

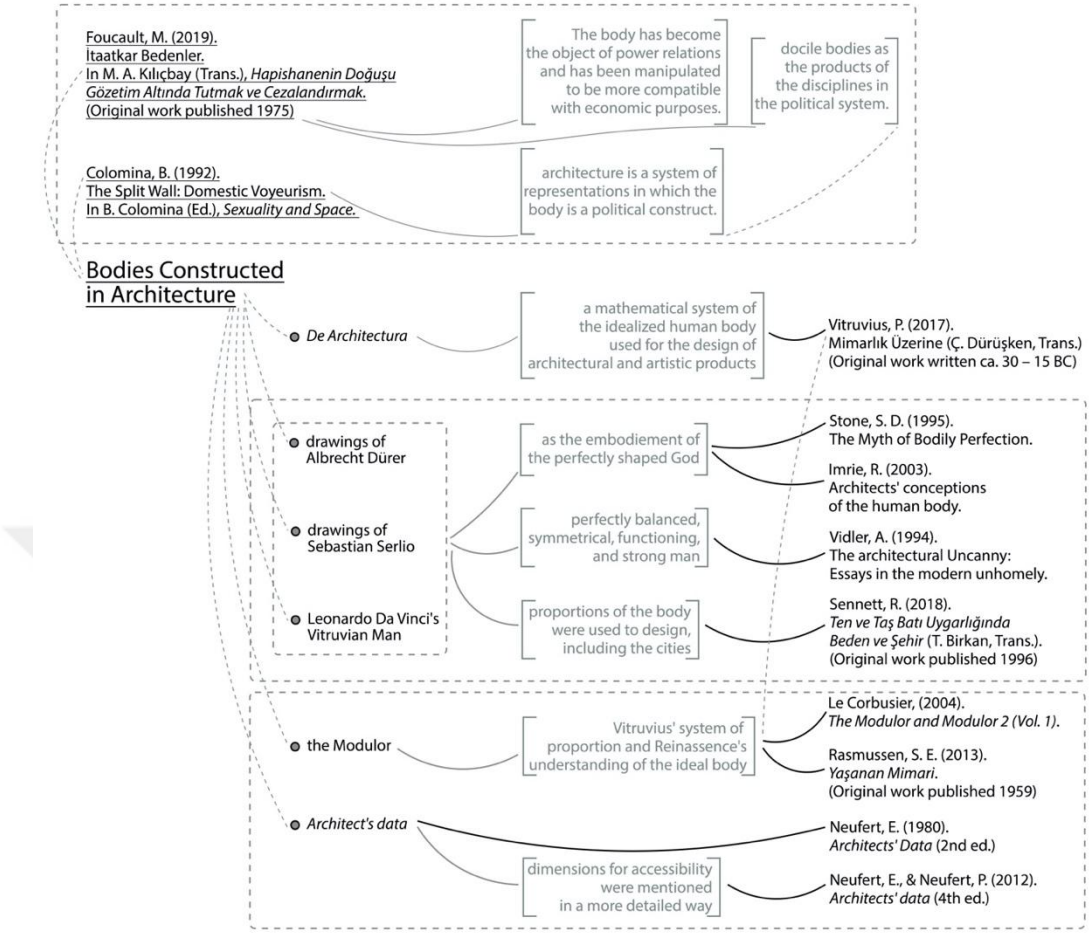


Figure 2.7 Map of the Bodies Constructed in Architecture

In another saying, the two examples of manipulating the human body for the sake of standardization have similar characteristics to Foucault's theory of docile bodies. They exemplify how the human body was constructed and manipulated by power relations for economic purposes in the architectural discipline. Power relations in architecture are also an essential topic of discussion in the materialist feminist theory. Elizabeth Grosz (1992), a feminist theorist studying architecture and gender studies, took an interest in representationally constructing the body, which she called body-politic, and said that those representations are not neutral or genderless as they are claimed to be (see also Hosey, 2001, p.104). Another feminist scholar, Leslie Kanes Weisman (1994), also mentioned the value-explicitness of discourse by saying that the male-centered language of architecture preserves the inequal and invisible status

of women. The words of Diana Agrest, a practicing architect and design theorist, can further clarify this idea. She (1988, p.29) suggested that anthropomorphism and symbolic order shaped the system of architecture, "which is defined not only by what it includes, but also by what it excludes.". So, the system of architecture, which represents the perfect human body with a male body, also constructed the imperfection of the female body, and the repressed identity of women (Agrest, 1988; Hosey, 2001). In the same vein, the ableist language of architecture perpetuates the inequality and invisibility of disabled bodies and constructs those bodies as abnormalities.

All in all, constructing an ideal body to be a standard is not a universal or neutral approach (Imrie, 2000). Conversely, that is celebrating a particular body typology (Vidler, 1994; Lefebvre, 1974/2019) while ignoring and marginalizing *the others* by designing a built environment that is only for the experience and expectations of those privileged bodies (Hamraie, 2013; Jones, 2014) who are "young ambulant males" in Vic Finkelstein (1990a) 's words. Or by the explanation of Richard Sennett, a professor of sociology and author of the book named *Flesh and Stone: The Body and the City in Western Civilization*, master images of the body can repress the ones with different bodies and make society "deny the needs of the bodies which do not fit the master plan" (1996/2018, p. 18). This situation results in constructing other bodies as the deviation from the norm, as the exception, the atypical, the unwanted, the problem (Aragall, 2003), similarly to the theory of social constructive approach. Alexa Schriempf (2001, p.70)'s words may also confirm discussing architectural bodies under the umbrella of social constructionist and feminist approaches:

> Classification takes place in a social context that is governed by norms that emerge, in part, out of our particular embodiments. If these norms depict certain bodies as 'able-bodied,' then other bodies are always already 'impaired.'

Likewise, Garland-Thomson (2011) reframed the construction of atypical bodies and coined the term *misfit*. She (2011, p.593) said that certain forms of embodiment are

constructed as fits and misfits by "the discrepancy between body and world, between that which is expected and that which is [...]". In her theory, fit and misfit refer not only to the bodies but also the degrees of harmony between the shape and function of the body and the designed space. To prevent misfits, the range of bodies accommodated in space should be widened, as Universal Design suggested.

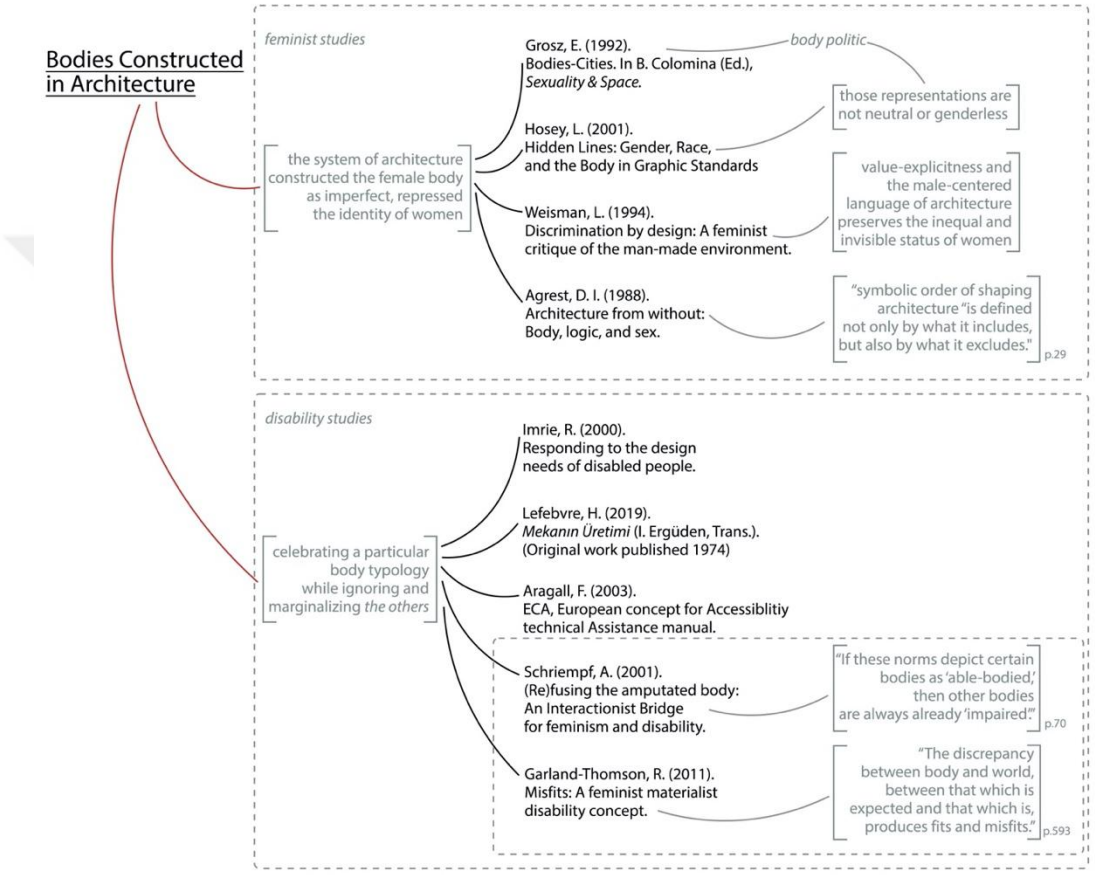


Figure 2.8 Map Illustrating the Critiques on Architectural Representations of the Body

There were several attempts to represent a wider range of body typologies in architecture and other design professions. Firstly, Henry Dreyfuss Associates redesigned their representations which formerly included data taken from able-bodied military men (Hamraie, 2012), in a way that they will include different age groups, ethnic groups, sexes, and abilities (Tilley, 2001). Moreover, in those representations, instead of using the golden section or any other theorem, the bodies

of sample groups were measured by following measuring setups, and the results were calculated for each group by standard deviation. Another example can be the illustrations of human measurements in the book named Raumpilot (Jocher & Loch, 2012); those illustrations did not only include an ideal man but showed figures of both sexes, different age groups, and bodies with different abilities (Zöllner, 2014).

In addition, Universal Design authors attempted to establish new anthropometric data sets that make bodily diversities be represented. One radical study for this purpose is the book named *Designing for the Disabled* written by Selwyn Goldsmith, a British architect and wheelchair user (Goldsmith, 1963). In this study, Goldsmith provided comprehensive data by representing the bodies of ambulant and semi-ambulant users and people using mobility aids with highly detailed technical illustrations and affected the British Standards Institution to shape the building access guidelines (Goldsmith, 1963; Myerson & Lee, 2011; Hamraie, 2012; Guffey, 2020). Even though the book was criticized for having outdated language, for example, using the word 'handicapped' to describe disabled people, giving place to stereotyped gender roles such as assuming that kitchens are only used by women, and focusing on mobile disabilities while ignoring others, it was an important step of its time (Guffey, 2020). In the fourth edition, Goldsmith published almost an entirely new book and gave place mostly to his own experiences (Goldsmith, 2011), and the ethical position of this book was seen as a guide, especially to government ministers (Imrie, 2001).

Another significant attempt to represent disabled bodies is the series of empirical studies conducted and reported by a team led by Edward Steinfeld, UD Principles author and founding director of the Center for Inclusive Design and Environmental Access (IDEA), for the U.S. Department of Housing and Urban Development. The studies aimed to provide valid and reliable data (Steinfeld et al., 1979) to be used to revise ANSI codes (Seelman, 2005; Hamraie, 2012). For this purpose, 60 individuals who used wheelchairs and a sample of able-bodied people were asked to perform simulated tasks in testing stations. The findings provided comprehensive data, including anthropometric measurements such as eye level and reaching, speed/distance measurements, wheelchair maneuvering and turning radius, push and

pull forces, and more. In 2000, by claiming that the previous anthropometric data set and the codes relying on it should be updated to comply with the changes in wheeled mobility technology and user demographics, Edward Steinfeld led a new study that was a decade-long and included 500 participants (Steinfeld et al., 2010; Steinfeld, Maisel, et al., 2010; Hamraie, 2012). However, as indicated in the report of the first study, people with similar disabilities have different functional ability levels; this is why the measurements shouldn't be used as the only source for designs (Steinfeld et al., 1979). Moreover, both studies focused on mobile disabilities, but there is great variability among people with disabilities, so there would always be a need for producing further knowledge.

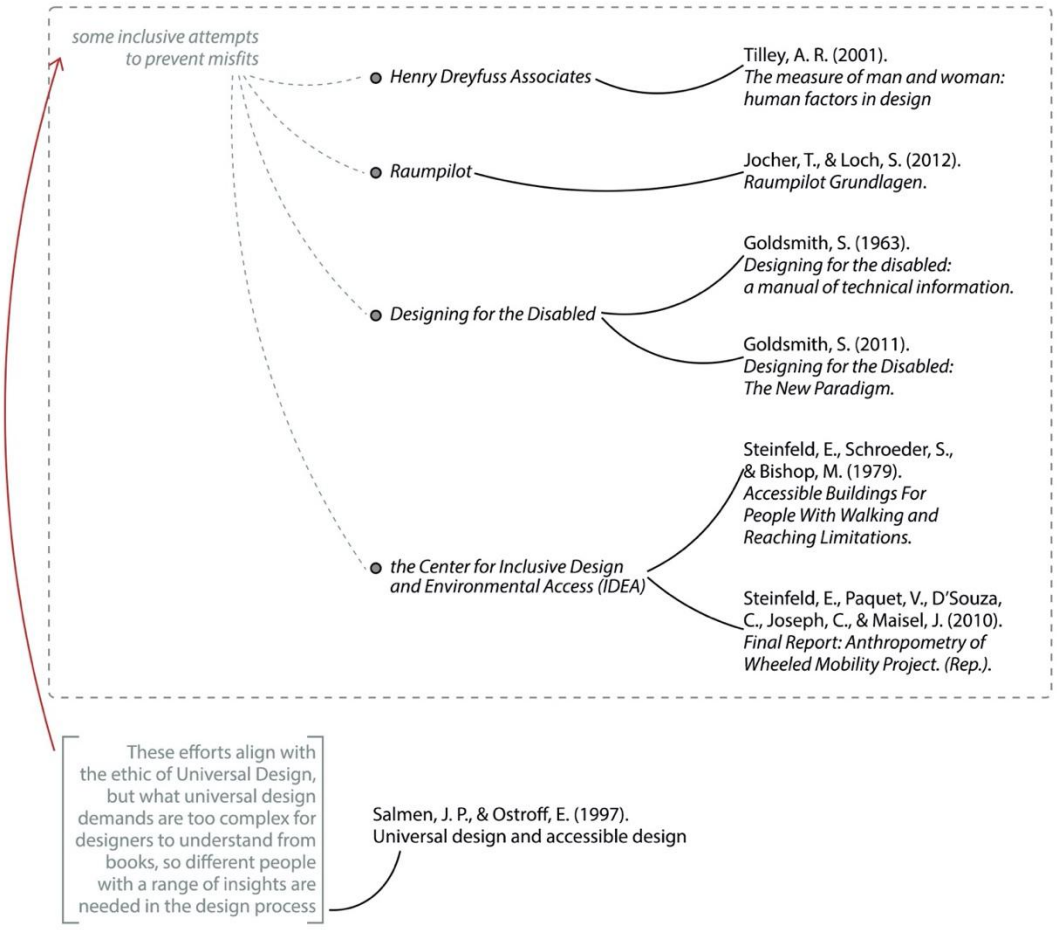


Figure 2.9 Map Showing the Attempts to Design Inclusive Representations

As said before, Universal Design is designing for all bodies, not for ideal standards. This is why the efforts that especially Henry Dreyfuss Associates had put into understanding differences by measuring a wide range of human bodies were described as a part of the ethic of Universal Design by UD proponents John P. S. Salmen and Elaine Ostroff (1997). However, they also claimed that what universal design demands are too complex for designers to understand from books, so different people with a range of insights are needed in the design process (Salmen & Ostroff, 1997). After embracing this understanding, it was seen that people with different bodies are encouraged to take place in the design process with various roles by universal design supporters. The ways that people with diversely able bodies participate in architectural design will be studied in the next chapter. But beforehand, the existing built environment, constructed primarily with an able body in mind, and its results in social structure, will be discussed under the umbrella of social constructive and feminist approaches.

2.3 Vicious Cycle in Social Structure

As discussed before, designing for a standardized body results in constructing bodies of fits and misfits in the built environment (Garland-Thomson, 2011). In the disability movement, sociologists showed the inaccessible built environment as the most apparent proof of exclusion and discrimination people with disabilities face in the world constructed for the norms of non-disabled (Morris, 1991; Hughes & Paterson, 1997; Barnes & Mercer, 2003; Siebers, 2008a). According to this understanding, the system of inaccessible social spaces constructs both the division of fits and misfits or the normalcy and the disability (Davis, 1995; see also Burcu, 2020) and the value system of a social hierarchy (Townsend, 1996) between these two "exclusive groups" of people (Shakespeare, 2006, p.185). However, according to Brisenden (1986, p.176), this blatant discrimination "has paradoxically been most clearly ignored, despite half-hearted efforts at legislation to rectify this situation.".

The reason for this ignorance can be the fact that only "when a different body appears, the lack of fit reveals the ideological assumptions controlling the space" (Siebers, 2008a, p.296) to privileged ones. But, for a long time, those different bodies have been removed from the sight of the able-bodied and located in residential institutions, special schools, sheltered employment, or at home (Finkelstein, 1991; Townsend, 1966; Linton, 1998; Schriempf, 2001). This segregation under the pretext of caring for the biologically unable ones caused the start of the disability movement (Hunt, 1981) and shaped the "theory and politics of" the movement (Hughes & Paterson, 1997, p. 328). However, the non-disabled society became so used to this situation that fighting for inclusiveness against segregation was considered breaking the social order (Linton, 1998).

Paul Hunt (1966, p.3), a leading figure in the disability movement, commented on the reactions of non-disabled people against disability and claimed that the "relationship with 'normal' people" is an essential part of the suppression of disability. Many other sociologists discussing social justice have emphasized the deep-rooted reactions of non-disabled society toward disability, such as "protectiveness, superiority, aloofness, revulsion" (Townsend, 1966, para.3), "arrogance" (Corbett, 1996), "fear of the unknown" (Barnes, 1996, p.48; Corbett, 1996), and "denial" (Lessing, 1981). Two correlated reasons were mentioned in literature for those reactions of the non-disabled world expressing the idea that the disability is something to be ignored and overcome (Lessing, 1981). Firstly, as mentioned above, scholars claim that our society's structure is built upon a social hierarchy (Townsend, 1966). By ignoring the needs of 'others', the group of able-bodied people aims to maintain and enhance their superior status in that hierarchical order (Corbett, 1996). The second reason mentioned by scholars why society ignores disabled people is that for able-bodied people, disabilities are "disturbing reminders of unwelcome reality" (Hunt, 1966, p.14). In a world, which idealizes the norm of the perfect body, people tend to reject any reminders of the possibility of tragedy, loss, pain, fragility, or diversity in humankind (Hunt, 1966; Corbett, 1996). To

believe these inferiorities can be avoided, able-bodied people label people with disabilities as "the other" (Wendell, 1997, p.268).

These acts of labeling and ignoring were discussed in different contexts, sociology and design, by scholars as "disabling culture" (Finkelstein & Ossie, 1996, p.172) or "epistemology of ignorance" (Hamraie, 2013, para.27). One of the most noticeable practices of disabling culture is marginalizing anything demanded by disabled people to participate equally in society. For instance, with the terms "special needs" (Corbett, 1996, p.3), "special education" (Finkelstein & Stuart, 1996, p.172; Barton, 1998, p.61), and "special" or "specialized" design (Story et al., 1998, p.10; Hamraie, 2013, para.7) taking place in our culture and social structure, the segregated and inferior status of the disabled group in the social system has been constructed.

In other words, sociologists believe that having a physical impairment is not when disablement starts in social structure, as said in previous chapters. Disability starts when this status of being special, and marginal has been given to one. The results of that status are being prevented from socially functioning to full capacity (Topliss, 1982) and not having autonomous lives as equal members of society (Bordas Eddy, 2017a). However, according to discussions in the literature, functional loss is not where the process of disablement has an end. Being unable to perform in social structure results in being an object of the care network (Finkelstein & Stuart, 1996). Then, the privileged group becomes even more superior with the title of the caregiver, reproduces prejudices against the differences, and believes that the 'others' are passive and dependent people (Townsend, 1966) with 'special' needs. As a result, negative labeling is repeated, disabling culture becomes permanent, and the inferior status of people with disabilities in the social system is reinforced. Scholars summarized this situation by expressing that disabling culture and ignorance make people with disabilities "victims of a vicious circle" (Brisenden, 1986, p.178; see also Bordas Eddy, 2017a; Burcu, 2020).

There are several examples of the concept of the vicious circle of disablement in the discussions of different sociologists. Firstly, Vic Finkelstein (1993, p.11) stated that

"the disappearance of cripples was a lengthy process which involved increasing acceptance of 'normalcy' as a creation of social integration" and explained this idea from the low-status image associated with disability. Especially in underdeveloped countries, people with impairments lose their chances to be a part of the workforce because of the barriers, and then they have no choice but to depend on charity or mendicity. So, having an impairment is identified with these inferior situations in the eyes of society, and disabling culture rationalizes its ideology as if there is no reason to remove the barriers causing disability in the first place for a dependent person unable to work.

Another example of the vicious circle was given by Colin Barnes and Geof Mercer (2003, p.42-48), who focused on the problem caused by 'special' schools. They claimed that special schools in which students with disabilities have few opportunities to advance their interests and are educated with a narrow curriculum cause the misconception that children with impairments are not smart enough or have low educational achievement. Consequently, the graduates of these schools are "located in less-skilled, low-paid jobs" if they have any chance of being recruited. And once again, disabling culture rationalizes itself as if there is no reason to make all schools accessible and enhance the educational opportunities of children with disabilities who would have unimportant jobs and not make a significant contribution to society.

All taken together, society's ignorance of meeting people's "needs in terms of appropriate human help, accessibility, and inclusion" (French & Swain, 2004, p.34) causes the effect of a vicious cycle of disability. The endless circle of disablement causes connotations of misfortune, unemployment, dependency, and incapacity being permanently associated with disability (Topliss, 1982) in the eyes of society. Further to that, being in this circle from birth or early childhood makes the person embrace the given identity and settle for limitations, inferior status, and isolation (Goffman, 1963/2009; Topliss, 1982; Morris, 1991; Burcu, 2006; 2020).

On the other hand, it would be wrong to say that society completely ignores this situation and does not take any precautions. As mentioned, authority owners tried to solve the failure in the social organization through laws. If we keep the discussion with the situations discussed before, it was aimed to integrate different social groups in recruitment and education, with several legislative attempts. For example, in the case of Turkey, it is obligatory to employ disabled workers in workplaces with a certain number of employees (İş Kanunu, 2003). In addition, in 2014, 'disability' was added to the article in the Turkish education law that all educational institutions should be open to all students without discrimination (Milli Eğitim Temel Kanunu, 1973). Whether these efforts have yielded satisfactory results is the subject of further debate. However, it will be helpful to recall Eda Topliss', the author of the book Social Responses to Handicap, comments on those attempts. Topliss (1982, 48) claimed that providing tax benefits and subsidies for recruiting people with disabilities is simply "accepting that a disabled worker is likely to be less productive than an able-bodied worker in the same job.". Or, placing children with disabilities in mainstream schools does not guarantee integration, equal education, or social participation (Topliss, 1982, p.19). As Finkelstein (1993) discussed, it is futile to try to change negative attitudes towards and consequences of disability without changing the inferior status of people with disabilities in the social structure. It is necessary to make much more serious decisions for this kind of radical social change (Finkelstein, 2004).

The social model aims to fight disabling culture and ignorance in society by removing barriers, invalidating negative labels, improving the self-esteem of people with disabilities, and building collective identity (Shakespeare, 2010). For these purposes, people with disabilities, who refuse to be labeled as "other", have tried different methods to break the vicious cycle, change the social structure, and eliminate ignorance. Since this study traces the transformation in the architectural profession, it would be helpful to look for methods used in disability movement to transform society.

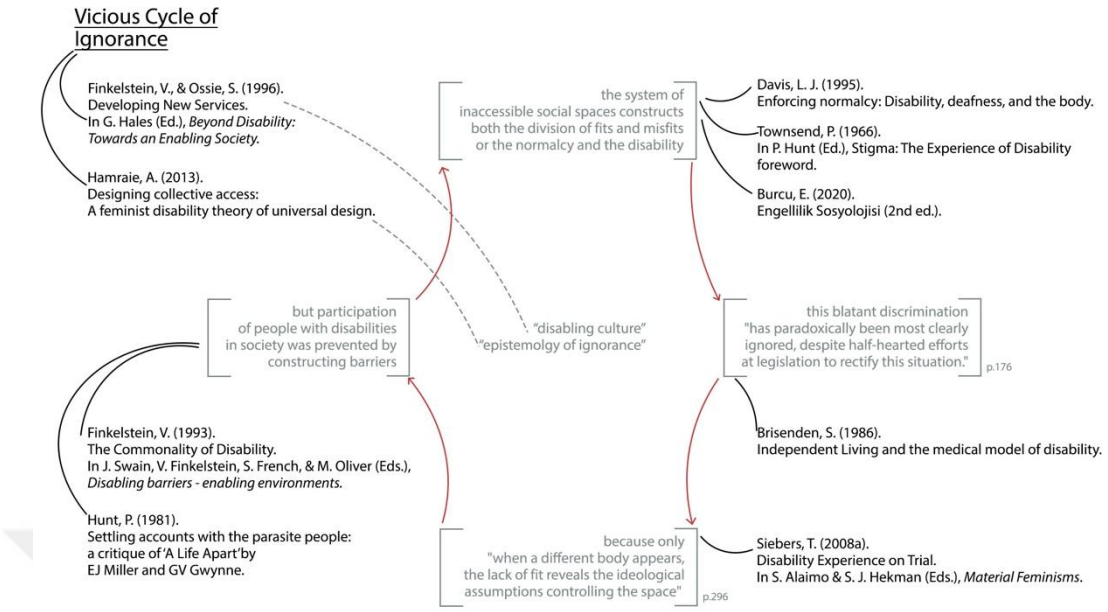


Figure 2.10 Map Summarizing the Idea of Vicious Cycle of Ignorance

2.3.1 Fighting Against Ignorance in Social Organization and Sociology

Susan Peters (1996, p.220-221), an academician studying education, disability, and teacher education at Michigan State University, discussed the methods used to be able to take part in society by people with disabilities. She mentioned three ways for this but preferred not to use one, "accommodation to the dominant societal group", since it is more about accepting the existing social order. She thought this way of living disability is "self-rejecting" and "asserting the victim mentality". Peters classified the other two methods as effective in the short and long term: "revolt and revenge" and “self-development”.

People with disabilities had used the first "revolt and revenge" method to point out the disabling practices and barriers in society (Peters, 1996) by practicing self-organization and direct action (Shakespeare, 1993). Many scholars agreed that the organizations established by disabled people, political acts of demonstrations, protests, and campaigns had a crucial role in shaping the social theory of disability,

establishing the disability movement, and gaining disability rights (Shakespeare, 1993; Barnes & Mercer, 2003; Barnes, 2004; Barton, 2004; Goodley, 2004).

One of the earliest examples of direct action was seen in 1935 when six people with physical impairments formed a sit-in protest in New York to bring attention to their being treated unemployable because of their impairments and their rights not being protected by law (Fleischer & Zames, 2011). Later, with the atmosphere created by the effect of the Civil Rights Movement in the 1960s, the disability rights movement also gained speed, and there were increasing numbers of demonstrations and organizations took place to change society's reactions and policies about disability (Barnartt & Scotch, 2001; Malhotra, 2001). During that period, the acts were given momentum with the effect of returning Vietnam war veterans injured in the war and dissatisfied with the accessibility codes and standards (Imrie, 2012). In the USA, people with disabilities continued protesting ignorance in laws and legislation under the umbrella of the organizations such as Disabled in Action (DIA, 1970) and American Disabled for Accessible Public Transit (ADAPT, 1983). Inaccessible public transit networks, bus companies, restaurants, post offices, and other places discriminating against people with disabilities were the target of protests, sit-ins, and lawsuits held by DIA and ADAPT. One of the most striking protests was organized by the ADAPT, in which people with mobility impairments crawled up the stairs of the Capitol Building to symbolize the exclusion of people with disabilities from society. This dramatic protest occurred while Congress deliberated over the American Disabilities Act (ADA) and resulted in one of the accomplishments of disability movements, the passage of ADA in 1990 (Malhotra, 2001; Fleischer & Zames, 2011). However, ADA was not enough to grant all the rights to people with disabilities, and disability activists continued to use demonstrations and protests to emphasize inequalities and barriers in the society of the USA. For example, recently, the Vessel structure at Hudson Yards, designed by Thomas Heatherwick, was protested for celebrating able body while excluding "people unable, unwilling, or uninterested in climbing stairs" (Anti-stairs club lounge at the vessel, n.d., para.1;

see also Gotkin, 2018; Shannon Finnegan and Aimi Hamraie on Accessibility as a Shared Responsibility, 2019).

Direct action took a significant part in the disability movement in Britain, like in the USA. The organizations, Campaign for Accessible Transport (CAT), Campaign Against Patronage (CAP), The British Council of Organisations of Disabled People (BCODP, 1981), Rights Now (1992), and Direct Action Network (DAN, 1993) held demonstrations to fight against the injustice they faced in the UK. To protest pitiful charity practices, workplace discrimination, unequal services, lack of step-free entrances to public places, inaccessible transport (see also Velho, 2019), and many other injustices, hundreds of people took the streets of different cities, especially London, in the 1990s. Those social movements resulted in the rights of people with disabilities being protected by the Disability Discrimination Act (DDA, 1992), which accepts for the first time in the UK that it is unlawful to discriminate against people because of their disability. On the other hand, these protests ironically revealed how society was constructed by ignoring the existence of people with disabilities. During the protests, many activists were arrested for breaking the social order; however, police had to de-arrest those people because of the inaccessible police vans, station building, and the magistrates' courts (Shakespeare, 1993; BBC, 2013; Rose, 2013; 2015). The vicious cycle of ignorance in social structure prevented power owners from using their powers on protestors.

While exposing the ignorance in society, those movements have also been challenging the negative labels associated with disability (Burcu, 2006), such as being passive and dependent (Shakespeare, 1993). Taking an active role against discrimination was the result of people with disabilities aiming to take control of their lives back (Shakespeare, 2006) and "doing it for themselves" (Shakespeare, 1993, p.251). Having control over their own lives is also the core understanding of the third method mentioned by Susan Peters (1996), “self-development”.

Peters (1996) believed that self-development of the disability community by giving place to voices of experience owners to generate the necessary knowledge in

transforming society is the one method that holds the most promise among others. When the emergence of the social model is considered, Peters' arguments may be examined and justified.

As mentioned above, in the 1960s, there was a rapid increase in the number and competence of disability organizations aiming to solve problems caused by disabling society. One of the initial organizations, Disability Income Group (DIG, 1965), was established to respond to the financial needs of people with disabilities by demanding higher help from the state. At first, many had supported DIG; however, in a short time, it became apparent that DIG had no intentions of empowering disabled people nor breaking the authority of experts on their lives (UPIAS, 1981; Finkelstein, 2004). Paul Hunt and other prominent figures of the disability movement claimed that experts were only working for themselves (Hunt, 1981), which is why they vehemently opposed the ideas of DIG and planned to establish a more emancipatory organization, UPIAS (Finkelstein, 2004).

UPIAS's principles, constructing the foundation of the social model, were built according to personal experiences mentioned by members (Oliver, 1996a; Finkelstein, 2001b). One of the problems and ideas that almost every UPIAS member shared was the interference of medical and other experts in their personal lives and that those experts should not be in charge of the fights against disablism (UPIAS, 1976). This understanding has continued to be an idea that both the social model advocates and criticals of the social model supported in disability theory. To give a few examples, Oliver (1996b, p.22; 2004) stated that it is an "imperative need for disabled people to become their own experts" for an independent and autonomous life. Likewise, Finkelstein (2001a, p.7) thought that being taken care of by non-disabled people is "processing our social death". Morris (1992), who criticized the social model, believed that, especially in the field of disability research, the lack of place given to people with disabilities causes problems. Similarly, Shakespeare (1996, p.213; 2006) believed that society "must enable disabled people to speak for themselves" because the actual expertise is having the experience. Many other researchers also emphasized the value of people with disabilities having a critical

voice in the decision-making process of any issue affecting their lives instead of able-bodied experts (Emery, 1981; Brisenden, 1986; Barnes, 2004a; Goodley, 2004; French & Swain, 2004).

With these discussions on expertise and experience, having the purpose of empowering people with disabilities in sociology and other fields was shown as a measure of genuinely studying disability (Hunt, 1981; Leaman, 1981; Abberley, 1996). Disability studies, which take steps toward a dynamic, active, and empowered disability understanding (Finkelstein, 1993), established the concept of "emancipatory research" (Morris, 1992; Barnes, 2004b). That concept briefly supported the idea that disability research should not take the people with impairments as the objects of study (Davis, 1995); instead, research studies should be in control of people with disabilities or disability organizations at all stages, from project finance to research agenda (Barnes, 2004b). Emancipatory research had gained power with the effect of the feminist approach; however, proposing the radical understanding of 'study only by those who have experienced an oppression at first hand' has led to some criticisms (Barnes & Mercer, 2003). Scholars mentioned three main critiques.

Firstly, it was claimed that emancipatory research understanding assumes that the researcher experiencing a disability is also knowledgeable about the experience of other people with disabilities (Barnes & Mercer, 2003; Shakespeare, 2006). However, conditions and experiences of disability are as diverse as the type and severity of impairments (Bérubé, 1998; Fine & Asch, 1988; French, 2004; Barton, 2004; Hughes, 2004); therefore, it cannot be concluded that someone with one impairment has a universal understanding of disability (Shakespeare, 2006). On the other side, disability scholars pointed out that the background shaped by having personal experience of disability may heighten the level of empathy and help to understand the oppression other people face (Hunt, 1966; French & Swain, 2004).

Secondly, emancipatory research resulted in rejecting non-disabled researchers studying disability, which opened the way for new critiques (Shakespeare, 2006).

Colin Barnes (2004a, p.31) thought the understanding that only people who experienced disability can study disability was "exclusionary and reductionist", which is not compatible with the philosophy of disability theory. Moreover, after claiming that many non-disabled people are affected by disabling culture, Shakespeare (2006) emphasized the contribution of non-disabled people to disability theory and the empowerment of people with disabilities. Even so, Shakespeare (2006, p.194) found it interesting that "many non-disabled researchers active in disability studies are themselves first degree relatives of disabled people". This fact may support the idea that disability experience may provide a new perspective on life (French & Swain, 2004) to both experience owners and close witnesses (see also Davis, 2000).

And lastly, this research approach was criticized for giving the impression that having direct experience alone would be sufficient for studying disability. The fact that companies started to apply to consulting organizations instead of disabled individuals for consumer participatory studies during the period when emancipatory research work gained strength could be used to support this criticism. The reason for this was shown as participation requires training in a specific field, the ability to exchange information in convenient formats, and the professional recruitment of individuals to ensure attendance (Mercer, 2004). Consequently, although the knowledge gained by direct experience of disability is invaluable, it would not be sufficient for an effective participatory study (Barnes, 2004).

After discussing those critical arguments, Barnes (2004a, p.31) suggests that creating "collective insight" for emancipatory studies is necessary. Understanding the role of both people with disabilities and non-disabled people and focusing on the partnership between those, truly emancipatory studies can be conducted (Barton, 1996; Shakespeare, 2006). Although some scholars found these ideas utopian, and the impact of those studies has not reached the point other scholars wished, research programs have started to evolve toward a participatory understanding with the support of universities (Barnes, 2004b).

Having mentioned to the universities, there are other methods of fighting ignorance found in literature additional but related to the ones Peters (1996) discussed. The first method is the change in academic culture proposed by Simi Linton (1998), one of the foremost Simi Linton experts in disability studies, arts, and culture. She (1998) defended that the academic curriculum should be reformed by including accurate representations of disability, and educational institutions should provide an inclusive academic environment (see also Davis, 1995). With the ideas that studying disability makes students gain a broader sense of humanity (Bérubé, 1998; Garland-Thomson, 2002), that the curriculum is a symbolic expression of cultural values and social relations (Kliebard, 2004), and that the partnership of differently-abled people in the faculties may cause social integration (Linton, 1998), a reform in academic culture would be an efficient tool to fight ignorance in society.

Another method used to challenge social structure was the paradigm of Independent Living (IL). Being defined as a social movement, IL was founded on the search for a better quality of life for people with disabilities with a right-based, user-led organization (DeJong, 1979; Mercer, 2004). The IL movement gained strength mainly among young people with disabilities who were actively involved in academic communities and who desired to fight against "the social death" expecting them in residential homes (Finkelstein, 1991, p.3), and this strength resulted in the setting up Centres of Independent Living (CIL) (DeJong, 1979). The first CIL was established in 1972 in Berkeley, California (Barnes & Mercer, 2003; Mercer, 2004) with the efforts of a well-organized disability community (Morris, 1991). The CILs have spread to the USA and UK, and more than 200 CILs were established in a short time. The cause of this popularity was the principles that shape life in CILs, which are "(1) disabled people were best qualified to determine their needs and how these should be met. (2) a comprehensive program of support was required (3) disabled people should be integrated as fully as possible into their community (Barnes & Mercer, 2003, p.116). Those principles can be interpreted as a radical critique of barriers in the able-bodied society (Mercer, 2004).

To conclude, the disability rights movements, people with disabilities taking an active role in disability studies, reform of academic culture, and the Independent Living movement all serve the purpose of increasing the visibility of people with disabilities in social life. Disability scholars believe that being enabled to participate in society, have a meaningful part in the workforce, have education in inclusive educational institutions, define their problems, and have a decisive voice in producing solutions would decrease the ignorance settled in society and be helpful to fighting disabling culture. On the other hand, as discussed in the previous chapter, having "impairment is simply a fact of life" (French & Swain, 2004, p.34), and thus according to sociologists, effective participation of all people in society is not possible (Abberley, 1998). To illustrate, some impairment conditions would not let people work seven hours a day, five days a week, or work at all (Shakespeare, 2006). In these circumstances, what should be done is not to be content that some impairments do disable people but to aim for social justice (Barton, 1996), to challenge the system of ignorance (Hunt, 1966), and remove the barriers that prevent people with or without impairments from participating to society as much as they are willing to.

Thereby, barrier removal has again shown itself as the prerequisite of participation, and it can easily be said that barrier-free environments are necessary for all the methods of emancipatory research, academic reform, and CILs to be adequately followed. With this understanding, I want to argue here that within the discussion of social structure, the vicious cycle appears between the notions of ignorance in society and barriers in the built environment. This is why the next part will focus on the other component of the circle, ignorance in architecture.

2.3.2 Fighting Against Ignorance in Architecture

A meaningful environment is
necessary and essential to a meaningful existence.

Weisman, 2000

Whether is an instrument of the power, as Foucault deduces, or a stand-alone revolutionary force, as Le Corbusier argues (Patrão, 2022), architecture has been discussed as a factor affecting social order and people's social functioning with the disabling barriers it produces (Jones, 2014). Although the disability movement always aimed for a barrier-free world, barrier removal was not considered as the optimal goal, but as an instrument providing participation and better life quality (Shakespeare, 2006). This understanding was followed by two supporting discussions by sociologists. Firstly, the social model scholars believed that for an efficient barrier removal plan, societies should not focus on the barriers but on the relations of oppression and institutional disablism resulting in them (Oliver, 1996a; Thomas, 2004a). This idea may also be used to support the barrier removal philosophy grounded in the Universal Design paradigm (Shakespeare, 2006), which targets the design system holistically instead of complying with regulations targeting singular barriers. Secondly, with the goal of participation in society, the disability movement not only aims to be visible in the public place but also to challenge the system of power relations and develop a respectable disability identity (Barton, 1996).

It has been discussed that the general understanding of the body in the architectural profession, in other words, the normate template, leads to the construction of misfits and the epistemology of ignorance which became extensive in the design thinking (Hamraie, 2013). When the suggestion of sociologists about focusing on the system of oppression, it can be argued that to break the vicious circle resulting in physical barriers being permanent in the built environment, this system of design should be reconsidered. Referring to the previously mentioned discussions again, scholars of the feminist approach to disability generated an analogy between the construction of gender and disability and proposed a dialogue between feminism and disability theory (Schriempf, 2001). Based on that idea, the disability movement can be guided by how women, as an oppressed group, had challenged architecture and the standardized male body.

Across the 1970s, the women's rights movement challenged the positions of women in various matters concerning life and demanded new options when necessary (Fine & Asch, 1981). During these movements, one of the demands of the women was to have a proper place reserved for women's needs (e.g., Cowan, 2012; Palinchak & Tan, 2019). Leslie Weisman (1994, p.1) commented on that demand by saying that "the appropriation of space is a political act, that access to space is fundamentally related to social status and power [...]". However, for Weisman (1994), the profession of architecture has ignored the spatial dimension of women's rights for a long time because of the prevailing discourse of architecture.

As discussed by feminist scholars, architectural discourse, including representations, drawings, photographs, and language, is built on gender distinctions (Colomina, 1992; Wigley, 1992; Rendell, 2000). For instance, as discussed in the constructed bodies in architecture, the anthropometric figures used to represent users have presented an image of male bodies (Agrest, 1988; Grosz, 1992). Lance Hosey (2001), an architect and author, related the gendered situation of the discourse to architecture being a male-dominated profession. Consequently, architecture had become a practice in which "men have created the built environment in their own self-image" (Weisman, 2000, p.1). To historians and theoreticians of architecture, this masculine mind of architectural discourse and architect resulted in ignoring women’s needs as users and spatial division of genders. In other saying, practices of placing women in houses (Wigley, 1992), constructing inhospitable streets (Rendell, 2000), and discriminating against them in public spaces and buildings by architectural design "reflected and reinforced" the oppression of women in society (Weisman, 2000, p.2).

For feminist scholars, the forms of resistance seen in architecture against gender equality (Wigley, 1992) were the result of that there was a lack of practicing female architects in the design professions (Weisman, 1994), and the male architects sustained the system which had given them the privileged status (Wigley, 1992). These ideas may be supported by the fact that with the increase in the number of female architects, Graphic standards began to include some representations of the female body (Hosey, 2001). Moreover, to enlighten this relation between the number

of female architects and the development of women's rights in architecture, some feminist historians focused on women's contributions to architecture (Rendell, 2000). These discussions support that the built environment is constructed according to the priorities and beliefs of the decision-makers (Weisman, 1981/2000).

Given the feminist discussions in architectural discourse, it can be concluded that the ignorance of the disabled body in architecture may be the result of the lack of architects with disabilities in the profession. Similar to the women's oppression, practices of spatial segregation by placing the disabled bodies in institutions, preventing people with disabilities from using public spaces, buildings, and transportation systems, and not considering the needs of people with disabilities as users may be the reflection of invisibility of diverse bodies in the architectural profession. However, recalling the given background knowledge about the emancipatory research concept in sociology may be beneficial for this discussion. Similar to the argument about researchers with disabilities, emphasizing the necessity of differently-abled architects to fight disablism in architecture is not meaning that only architects with disabilities can design accessible environments or that all non-disabled architects are supporters of disablism.

The main philosophy of these discussions is to offer a partnership between architects with different abilities, and it was thought that able-bodied architects could benefit from this partnership. As explained by Richard Sennet (1996/2018), the comfort that bodies have in an environment thrusts the body into a state of rest and prevents it from having a dynamic relationship with the environment, in other words, comfort results in ignorance. But, living, working, and studying alongside a body with disabilities may generate an understanding of the disability of the able-bodied architect. As Steven R. Smith (2011), the author of the book Equality and Diversity, suggested, learning from the 'other' to construct liberating and non-oppressive systems necessitates positive engagement with the 'other' by having them within the structure. Then as well, able-bodied architects may learn how to enable people with design from design partners architects with disabilities.

So far in this study, the answers of the first two research questions about the sociological and conceptual foundations of the idea that people with disabilities should be placed in the structure of architecture were discussed. In the next chapter, the fight against epistemology of ignorance and disabling culture in the architectural profession will be traced, to answer the remaining question.

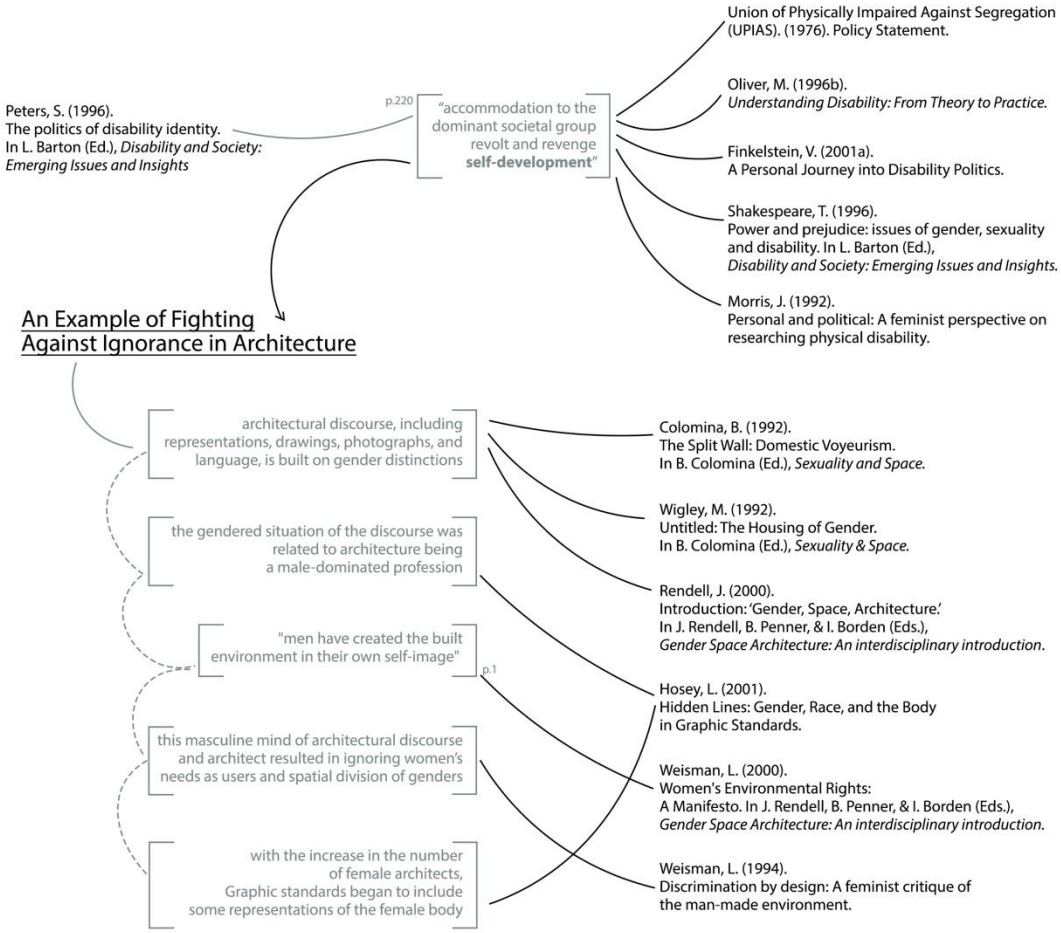


Figure 2.11 Map Illustrating the Idea of Self-Development to Fight Against Ignorance with the Case of Female Rights in Architecture

CHAPTER 3

PARTICIPATION OF PEOPLE WITH DISABILITIES IN ARCHITECTURE

Nothing about us without us.

Charlton, 1998

James Charlton (1998), Executive Vice President of Access Living in Chicago and lecturer on disability, explained that disabled people demand to be the political and influential voice of their problems in his book named by the axiom *'Nothing about us without us'*. He said that when abled-bodied people speak on behalf of disabled people, their rights will become conditioned by dependency. And this situation can cause social degradation, subordination, inferiority, and another way of constructing oppression. This is why Charlton (1998) suggested that political, economic, cultural systems should realize the necessity of disabled people's participation in decision-making processes, and the importance of their experiential knowledge to understand anything about disability.

When the disability rights and architecture profession is thought, it can be seen that the rights of disabled people in the architectural environment were generally advocated by disabled activists and architects. Although, there are people with able bodies who also contributed to the disability studies in the fields of both sociology and architecture, people deeply concerned with barrier-free architecture are often people who have a close relationship with disability, such as Ronald Mace and Selwyin Goldsmith (Bordas Eddy, 2017a). The reason for this situation can be the fact that knowledge gained with experience of disability, makes people be able to detect barriers more easily than others (Liebergesell et al., 2018). Mark Priestley (1998, p.85) has also pointed out the importance of experience by saying that; "[…]

Disabled people's experiences will always be the most immediate way of identifying barriers […]".

The experience of disabled people may be a beneficial source to achieve the universal design. With this understanding, the philosophy of UD will be examined in the following part, to find the traces of the relationship between the theories of participatory design and universal design. In the design professions, there are several examples of that disabled people participated in design processes at different stages and degrees. In the rest of this chapter, the participation methods used in literature, from evaluating the final design to taking part in the process as a designer, will be studied. And finally, the architects with diverse abilities and their contribution to architecture will take place.

3.1 Philosophy of Designing for All Abilities

Universal design is socially integrating,
functional for everyone and inspiring as well.

Steinfeld § Tauke, 2002

By claiming that designers and architects gives reference to certain body typologies as spatial inhabitants and thus that built environment has a role on constructing categories of abled and disabled bodies (Lifchez, 1986) the idea that built environments are not socially, politically, or culturally value-neutral was supported (Weisman, 2000; Hamraie, 2013). As said before, to bring social justice for diverse bodies to designed environments and to be a critic of value-implicit designs (Steinfeld & Tauke, 2002; Hamraie, 2013), Universal Design paradigm[2] was

[2] The paradigms of Design for All (DfA) and Inclusive Design (ID) have a very similar goal to UD, even though their literature backgrounds and geographical origins show differences. In some studies, it was preferred to use all three terms as synonyms (e.g., Heylighen et al., 2009b; Ielegems et al., 2021), so a similar approach was followed, and all three of these terms were used to refer to respecting all user needs in this study. For more information, please see Appendices A and B.

established and to make it easier to understand, guiding principles of UD was set by scholars (Steinfeld & Maisel, 2012 p.72). However, Universal Design is not about designing for disabilities or misfits, nor coming up with an end product by following seven principles (Salmen, 2011; Hamraie, 2013), which can be changed through time (Lin & Wu, 2015) or be expanded further (Ginnerup, 2009). According to Rob Imrie (2012), instead of propagating techniques and principles, Universal Design demands a deeper engagement with its "philosophical and theoretical basis". And he (Imrie, 2012, p.880) argues that the challenge of UD is not designing barrier-free environments but "to develop a politics of design that will challenge, and overturn, the sources of disablement within society.". In addition, Edward Steinfeld and Jordana Maisel pointed out a similar situation in their book named Universal Design: Creating Inclusive Environments (2012, p.67-68, p.91), by saying that universal design has a "distinctive identity" that differs from its precursors, such as accessibility and barrier-free design in which there is a focus on complying with regulations (Steinfeld & Tauke, 2002).

To better understand the philosophical basis or identity of Universal Design, the characteristics of UD must be studied. To begin with, even though there are some misconceptions about Universal Design even among design professionals (Steinfeld & Maisel, 2012, p.68), UD is not a method to provide access (Salmen, 2011) by special design or an assistive technology (Sanford et al., 1998; Steinfeld & Maisel, 2012; Imrie, 2012; Hamraie, 2013) added later on the initial design. The reason is that those design features draw attention to the bodily state, signalize a medical model understanding (Hamraie, 2013) by strengthening the idea of some bodies being the exception to the rule (Aragall, 2003), and cause spatial segregation and stigmatization (Sanford et al., 1998; Steinfeld & Tauke, 2002; Knecht, 2004; Steinfeld & Maisel, 2012) which are kinds of oppression according to social model (Weisman, 1994; Burcu, 2020). On the contrary, universal design is a social justice method to overcome all kinds of exclusion of marginalized identities such as different ages, sexes, sizes, weights, physical and sensory abilities, emotional and cognitive states, and intersections or overlapping of those (Hamraie, 2013) without

highlighting differences. That is to say, instead of protecting the spatial rights of a specific group of people by complying with regulations, the Universal Design philosophy supports the idea of considering the needs of all, including the ones with disabilities, to assert innovative solutions (Steinfeld & Tauke, 2002; Knecht, 2004). These creative UD projects may result in shared experiences and interactions within society instead of separation (Linton, 1998). Furthermore, it is believed that when the environment is designed with UD philosophy, the need for specialized technologies will be decreased (Aragall, 2003).

The second feature of the Universal Design philosophy is valuing innovation and knowledge production (Hamraie, 2013), unlike barrier-free design. For the latter, which relies on accessibility standards, even though the amount of knowledge increased, it is more about the details in regulations rather than disability experience (Steinfeld & Tauke, 2002). On the other hand, UD scholars claim that the situated knowledge and the resources used to justify and produce that knowledge are the reasons why designers struggle to develop design solutions for all people (Salmen, 2011; Hamraie, 2013). The first source, as said before, is regulations and standards, which were criticized for providing misleading knowledge (Steinfeld & Tauke, 2002; see also Mankan, 2019) and promoting add-on solutions by UD. The second resource is the existing anthropometric data, whose validity was questioned for not representing the diversity of human nature (Hasdoğan, 1996), relying on the normate template (Hamraie, 2012), and thus creating misfits (Garland-Thomson, 2011). And thirdly, when there is not enough reliable data, architects design by relying on knowledge based on their own experiences and insights (Sanford et al., 1998), and this method may create a gap between the users and the designer (Aragall; 2003; Hamraie, 2013). According to Universal Design proponents, the lack of understanding and the unorganized and inadequate knowledge are the main obstacles standing in the way of universal design being mainstream in practice (Sanford et al., 1998; Salmen, 2011; Steinfeld & Maisel, 2012; Hamraie, 2013). Consequently, it can be said that Universal Design presupposes constant knowledge production about people's abilities, needs, and preferences (Sanford et al., 1998) and renovation in the

methods of providing knowledge. Contrary to existing methods, one immediate and effective way of receiving further information usable for UD is to consult the experience and perspective of people who face exclusion in designed environments (Sanford et al., 1998).

The necessity of knowledge production can be related to another feature of Universal Design philosophy with the words of John Salmen, an expert architect/scholar in barrier-free and universal design. He (2011) said that "As more is learned about human needs and abilities, and as technologies develop, the practice of universal design improves, evolves, and changes.". This evolving characteristic of Universal Design makes it a process instead of research for an optimal end product (Sanford et al., 1998; Bühler, 2001). Furthermore, Edward Steinfeld (2008, p.815), coined the term "Universal Designing", meaning that it is "going there, rather than getting there" (Steinfeld & Tauke, 2002, p.188), and emphasized the idea that universal design is an improvement and innovation process (Steinfeld & Maisel, 2012, p.67). So, being critical of UD strategies, bringing new discussions, and designating new methodologies can be considered as a part of Universal Design Philosophy.

In this innovation process, Universal Design was improved with different approaches to address the scope of inclusion and the strategies (Hamraie, 2013); for instance, the feminist approach (e.g., Weisman, 1994) affected the UD understanding of the social construction of disability (Garland-Thomson, 2011) and about spatial inequalities (Steinfeld & Tauke, 2002; Hamraie, 2013). With the effect of other approaches, an objective, discussion, or new methodology was added to the universal design philosophy (Hamraie, 2013). Considering the discussions mentioned above, when the universal design philosophy is defined as a social justice process that presupposes knowledge production, scholars discussing the methodology of Participatory Design as a humanitarian approach to operating Universal Design would be well-reasoned (e.g., Herssens & Heylighen, 2007). Giving a voice to those affected by designed products in the decision-making process indicated before by the proponents of Universal Design to achieve UD in practice (Salmen & Ostroff, 1997; Sanford et al., 1998; Steinfeld & Maisel, 2012). In the next part, the literature about participatory

design methodology being used to develop Universal Design will be discussed in consideration with the given features of UD philosophy.

But beforehand, it should also be mentioned that the importance of participation in the design process took place in national and international action plans since the parallel developments in the political environment were always discussed in this study. To start with, the involvement of users and cooperation were shown as essential stages of "The City for All Plan", designated by the European Concept for Accessibility (ECA) in collaboration with the Luxembourg Ministry of Family, Social Solidarity, and Youth (Aragall, 2003). Similarly, in the II. Özürlüler Şurası (2005A, 2005B) in Turkey, there was a strong emphasis on the importance of participatory design. While discussing the problems in the physical environment, it was said (2005A, p.8) that disabled people should have an influential voice in decision-making about themselves and the cities they live in. Council (2005B, p.3) also pointed out that the built environment should be designed for everyone, and for this purpose, all processes of organizing, researching, planning, designing, and application should be carried out in collaboration.

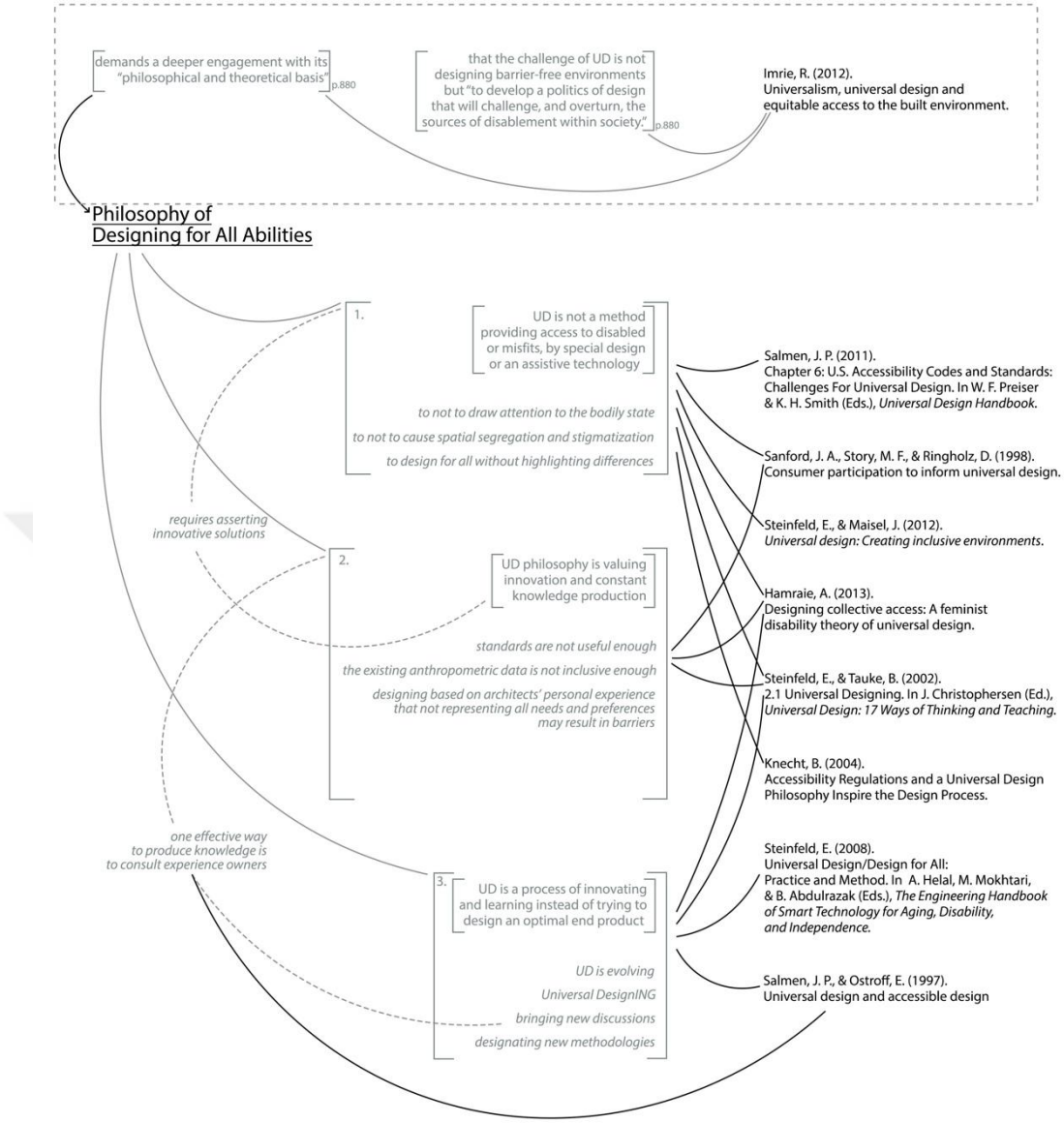


Figure 3.1 Map Summarizing Design For All Philosophy

3.2 Participatory Design Approach

As discussed before, the absence of adequate and organized knowledge is one of the obstacles that prevent designers from responding to all user needs, abilities, and preferences (Sanford et al., 1998; Imrie, 2000; Bühler, 2001). This is why knowledge production is seen as a critical requirement for Universal Design. According to the early proponents of UD, knowledge production should be based on input from people

with diverse abilities, especially older people and people with disabilities who are mostly not included in design research (Sanford et al., 1998).

There are two main reasons to support that idea. Firstly, as mentioned before, there is a close relationship between bodily experiences and knowledge of space (Pallasmaa, 1996/2011; Merleau-Ponty, 2017; Lefebvre, 1974/2019). So, it can be expected that particular experiences of disability can make people gain a new perspective and knowledge about architectural space (Heylighen et al., 2009a; Pivik, 2010). The other reason is that facing challenges makes people with disabilities and, in some cases, their caregivers become creative problem solvers to improve the quality of their lives (Miller et al., 2004; De Couvreur & Goossens, 2011). Such that in the online platform named patientslikeme.com (2005), people with different health conditions share tips they innovated for multifarious situations. One of the examples is to create visual and auditory cues to prevent the falling and freezing of gait that people with Parkinson's disease commonly experience when facing turning corners, doorways, or changes in the flooring; another suggestion was using a rolling laundry basket, grabber stick, or a seat next to the washing machine to simplify household chores for people with a health condition (Patientsikeme, 2019). Many other creative solutions, from reacting to stigma (PatientsLikeMe, n.d.) to going to a theme park with a wheelchair (Hannon, 2021) which were generated with the perspective of experiencing a health condition, take place on this website.

Elaine Ostroff (1997), one of the members of the team establishing Universal Design Principles, also emphasized the ability to develop strategies for coping with difficulties of everyday life and coined the term user/experts to define experience owners. Moreover, she claimed that especially where the needs and limitations of users are not familiar to designers and their life experiences, designers can benefit from the knowledge of disabled people as valuable resources for practicing universal design. To put it another way, as suggested by scholars, the design and evaluation processes should be supported by the participation of diversely abled people, especially the end-users, to have practical results of UD (Salmen & Ostroff, 1997; Bühler, 2001; Ginnerup, 2009). That, involving the insight of the potential users in

the design processes through various co-design activities to develop new approaches, is the base of another movement named Participatory Design (PD) (McClelland & Suri, 2005; Binder & Brandt, 2008; Sanders et al., 2010).

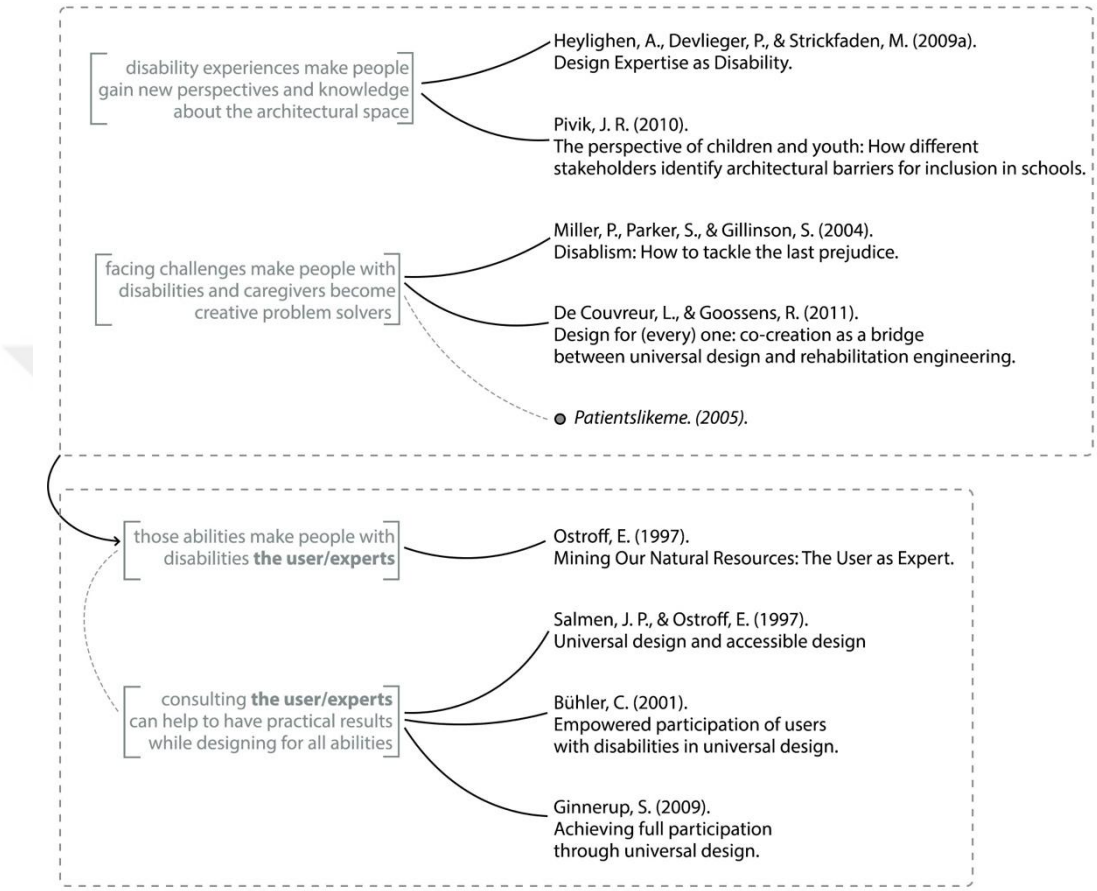


Figure 3.2 Map Illustrating the Development of the User/Experts Idea

Being affected by the atmosphere of the 1960s, design theoreticians searched for ways to increase user satisfaction and create more humane environments (Sanoff, 2000), which they defined as providing equality, inclusiveness, and respect for every user (EDRA, n.d.). With the critique on experts/architects for tending to serve the power which ensures their privileged position over 'others', scholars supported that "empowerment" of all or a humane environment can be achieved by participatory architectural practices (Lipman & Harris, 1998, p.8). In other words, questioning the relationship between the designer/architect and society and trying to reconstruct professional boundaries and power relations in design disciplines by challenging

how and by whom values are created were the main goals of Participatory Design (Sanoff, 2000; Jenkins, 2010a). Organizations conducted by the Environmental Design Research Association (EDRA, 1968) and studies conducted by Henry Sanoff (2000), the founder of EDRA and a professor at North Carolina State University, took a significant space in the history of the PD approach (Jenkins, 2010b). Furthermore, PD has been used to challenge existing assumptions and practices of different disciplines, such as the design of computer systems (e.g., Muller et al., 1993), product design (e.g., Hasdoğan, 1996; Jacobson, 2021), urban design and planning (e.g., Sanoff, 2000; Ataöv & Haider, 2006; Severcan, 2015), and architectural design. However, although PD is not a new method and shares some similarities with the Universal/Inclusive Design ideology (Luck, 2003), it was seen that the purposes and the methods of applying user participation for designing for all abilities have evolved within the universal design philosophy.

One of the fundamental changes seen in Participatory Design within UD is the purpose. In the earlier examples of PD, user groups with certain needs and abilities participated in design processes to increase the compatibility of specialized, assistive devices and products for those users (Sanford et al., 1998). Conversely, participation in achieving universal design demands a more inclusive understanding since the user group of universal design is accepted to be broader than that of specialized design. Moreover, as given before, this kind of practice is against the base characteristics of the universal design philosophy, not highlighting bodily states to prevent stigma. In the UD process, as the members of The Center for Universal Design, Jon A. Sanford, Molly F. Story, and David Ringholz (1998) summarized, the user involvement method was used to define user needs (see also Aragall, 2003), to develop regulations and standards (see also Ginnerup, 2009), to conduct research for design exploration and education (e.g., Murrow, 2001), and to evaluate the end products (see also Preiser, 2001) with the ultimate aim of design for all.

The other change in Participatory Design is the methodology of practice that the Universal Design philosophy demands. In many examples of PD, the user's participation has generally been provided in the late phases of the design projects to

test the prototypes or the end products (Bühler, 2001; Visser et al., 2005; Lin & Wu, 2015). On the one hand, those evaluation studies have been helpful for criticizing existing designs and increasing the effectiveness of UD solutions to a certain extent (Sanford et al., 1998). For example, in some cases, a redesign can be possible, or user feedback can be used in future designs (Preiser, 2001). But on the other hand, there are several downsides to this method of participation that make it necessary to establish new approaches. First of all, as discussed before, Universal Design is a process and requires its philosophy to be present throughout the design. Leaving the process to the designer and involving the user only in the testing phase (see also Lin & Wu, 2015) for the sake of UD is not compatible with this philosophy. Secondly, according to the scholars studying participatory design, the success of the participation depends on the users having an active and decisive role (Miller et al., 2004; Binder & Brandt, 2008). The reason is that the methods in which users do not involve in the design process reproduce the passive, conceptual, scenic, disempowered role of the user (Jones, 2014). But, as said, diversely abled users can create new solutions, so they should take place at all levels of the design process as active decision-makers (Miller et al., 2004; Ginnerup, 2009; Jones, 2014). And lastly, instead of testing the prototypes and applying redesign, if possible, it can be more logical to consult the users from the early planning stages to save time and money (Sanford et al., 2008; Bühler, 2001).

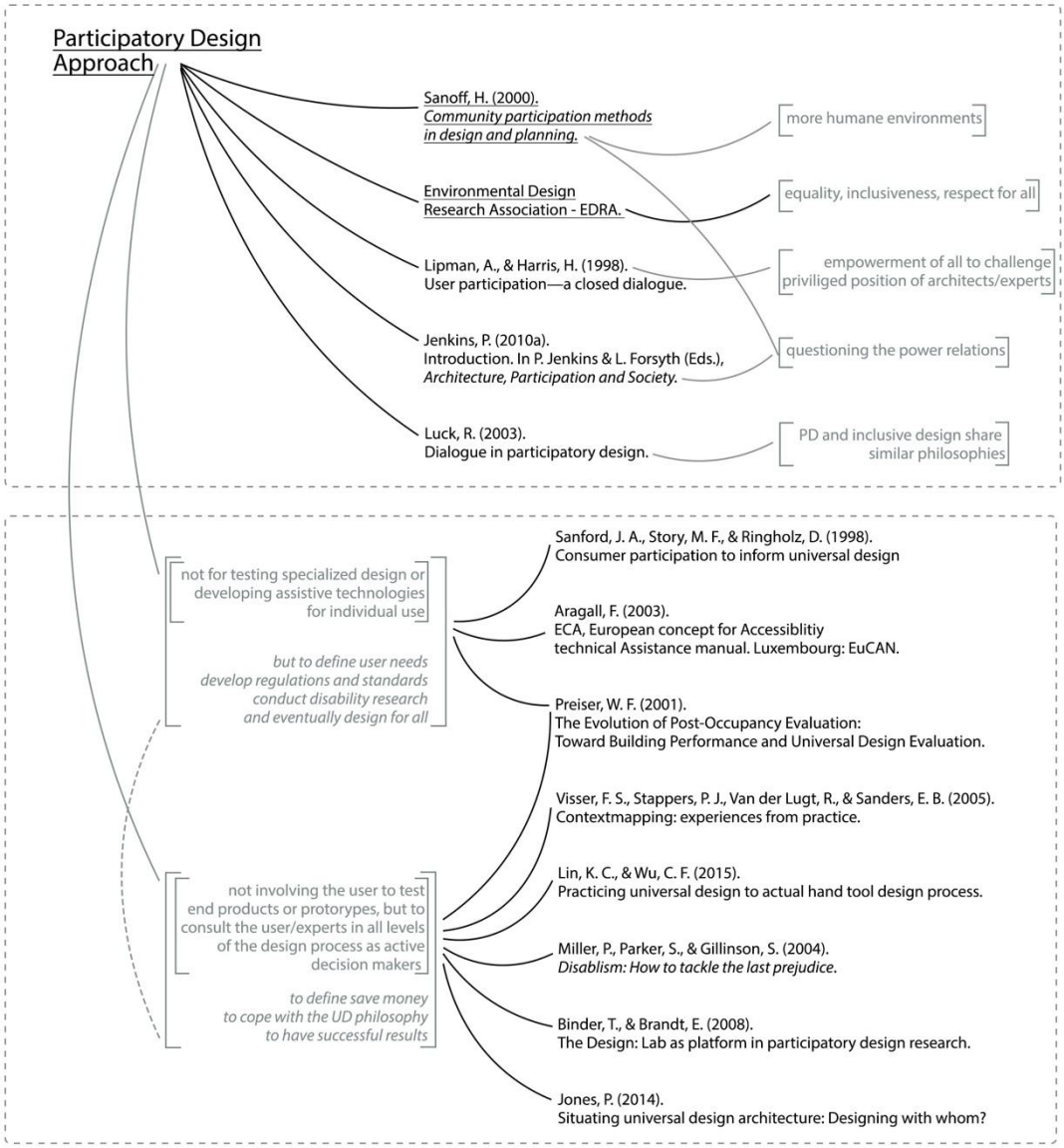


Figure 3.3 Map Illustrating the Participatory Design Approach

In other words, the influence of the user on design decisions varies depending on the method used for the participatory design (Wulz, 1986). However, engaging and involving the experiential knowledge of the users in an efficient way to achieve U.D. is a challenge for designers (Sanders et al., 2010; De Couvreur & Goossens, 2011). Various forms of participation have been used in design professions, and design researchers have conducted several studies to name, test, and compare those ways. For example, in her highly influential article about citizen involvement in planning,

Sherry Arnstein (1969, pp.216-217) claimed that there is a significant difference between allowing participation for the sake of doing it and having the end product affected by the participatory process. With that idea, Arnstein designated an eight-rung ladder showing the degrees of "decision-making clout" offered by different participation methods. Then, she grouped those methods under three titles: "nonparticipation", "degrees of tokenism", and "degrees of citizen power". Similarly, Fredrick Wulz (1996) put participation methods in order accordingly to their effect on the decisive power of the designer. Another scholar, Paul Jenkins (2010b, p.13), director of the Centre for Environment and Human Settlements and research professor at Edinburgh College of art, classified the forms of participation as (1) providing information/one-way flow, (2) consultation/two-way flow and (3) negotiation. And lastly, Elizabeth Sanders (2006), an associate professor with expertise in participatory design at the Ohio State University, Department of Design, demonstrated the blurred boundaries between participation methods in a cognitive collage showing the topography of design research to the date of 2006. In this collage (2006, p.4), participation practices were placed between two edges: "users seen as reactive informers" (mostly seen in the U.S.) and "users seen as active co-designers" (mostly seen in Northern Europe) and the changeable characteristics of practices in time were pointed out. Being affected by all, this study will be continued by discussing participation methods and related studies under three titles, which are aligned according to the degree of user involvement they provided, although having some interweaved ideas.

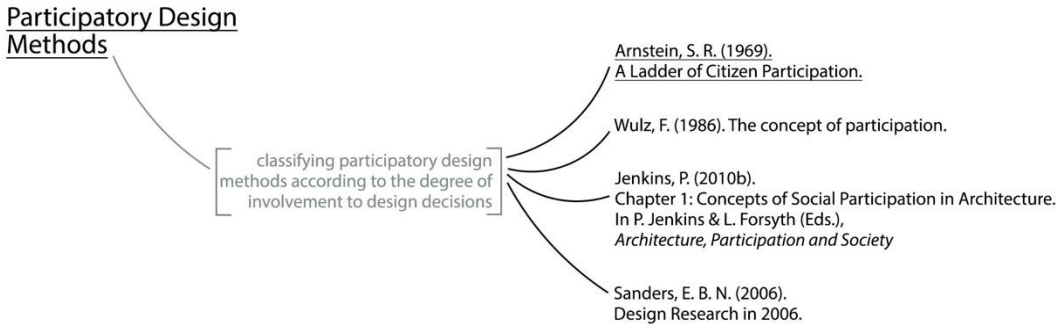


Figure 3.4 Map Showing the Studies Classifying Participatory Design Methods

3.2.1 Passive Participation by Being Represented

The user has always had a significant, central role in the design processes since there is a dominant philosophy of "designing for people" (Myerson & Lee, 2011). However, the user has generally been a scenic concept, and users had a passive presence in design (Jones, 2014). In his study of analyzing different forms of user participation in architectural design, Fredrik Wulz (1986) assigned this scenic presence of the user as the most passive form of participation and named it the method of "representation". In this form, the designers put themselves in the user's place and try to preassume the personal needs and preferences of the users by taking reference from their knowledge and experiences (Wulz, 1986; Hasdoğan, 1996), the validity of relying only on designers' perspective was discussed in the previous chapters. Moreover, the representation method is used in testing processes in which the designers or their colleagues pretend to be the user to evaluate the strengths and weaknesses of the design (Myerson & Lee, 2011; Cardoso & Clarkson, 2012). This method took place in literature with different names, such as self-modeling (Hasdoğan, 1996) or role-playing (McClelland & Suri, 2015). However, in all names, the necessity of great insight and empathy were emphasized since the representative has to exemplify different user groups with various abilities.

With the idea that the information is more engaging when combined with personal experience, another form of role-playing, which has been used by other professions (e.g., Clore & Jeffery, 1972; Livingston, 2000), was suggested by scholars to create the needed empathy among designers (McClelland & Suri, 2015; see also Cardoso & Clarkson, 2012). In this form, designers try to generate ideas about elderly or disabled users' abilities and limitations in situ by a capability-loss simulation exercise (McClelland & Suri, 2015; e.g., Toshiba Corporation, n.d.). These exercises were seen as valuable inspiration sources by a group of scholars for providing first-hand exploration and being suitable to be used at any phase of the design process (McClelland & Suri, 2015). Furthermore, they supported that simulating capability loss can be beneficial to teach UD to design students as well. For example, in some

design courses, students were asked to perform everyday tasks in the campus environments while using crutches, wheelchairs, canes, or being blindfolded to be more aware of the relationship between the physical environment and disability (e.g., Chang et al., 2000; Altay & Demirkan, 2013; Ergenoglu, 2013; Mulligan et al., 2018).

On the one hand, simulation exercises were supported by scholars for being helpful in gaining knowledge and changing attitudes about disability. But on the other hand, it was questioned if the role-playing exercise could relate the problem to the disabling environment since the exercise focuses on the people's bodily limitations (Finkelstein, 1980). This is why a group of scholars criticized the exercises for being inappropriate in the context of the social model of disability (French, 1992; Burgstahler & Doe, 2004). For these scholars, acting as a disabled person for a short time is not simulating disability in all aspects but simulating the difficulties and thus raising some negative feelings, reinforcing stereotypes, and giving rise to misconceptions about disability (Lifchez, & Winslow, 1979; Scullion, 1996; Herbert, 2000).

However, Burgstahler & Doe (2004) also claimed that disability simulations can still be used as a learning tool if they are well-designed, and created a guideline for this purpose. In this guideline, involving a participator with a disability was mentioned as one of the critical points. With the contribution of people with disabilities, it was believed that students could gain a broader perspective about disability than only simulating impairments (Herbert, 2000). For example, Chang et al. (2000) and Ergenoğlu (2013) involved both guests who have disabilities and simulation exercises in the design courses they designated to generate insight among students and mentioned the effectiveness of this corporation.

Another example is the workshop conducted by Özlem Belir (2021) with the participation of Dr.Carlos Mourao Pereira, an architect with visual impairment. In this workshop, architecture and landscape design students were asked to experience the Darüşşifa section of Sultan II Bayezid Complex while being blindfolded. With

the guidance of Pereira, students gain the perspective of experiencing the space with the features of temperature changes, acoustic differences, and texture and designing for all senses. A similar study was conducted in the scope of an elective course on inclusive design at Katholieke Universiteit Leuven (KU Leuven), Department of Architecture, by Ann Heylighen and Peter-Willem Vermeersch (2015). In this study, architecture students were asked to observe the spatial experience of people with various disabilities, who were named user/experts in the study, while walking through the university buildings with them. Unlike Belir (2021)'s study, researchers preferred not to use disability simulation exercises by referring to the abovementioned critiques. Research also analyzed the effect of building visits on students by asking them to submit a report involving their comments on the course. The students' writings cleared that the interaction with user/experts raised awareness about "the impact of the built environment on people's life", "diversity" of spatial experiences, and "limitations of empathy" in figuring out other people's experiences (2015, Findings and Discussion, para. 2-6). In their study, Heylighen and Vermeersch (2015) emphasized the importance of conducting such studies in undergraduate education and changing the mindset of future architects to achieve inclusive environments since attitudes gained in academic life continue to exist in professional life.

Ann Heylighen also conducted another walking-through with user/experts study to explore the idea that the well-intended UD solutions could be experienced differently by people with disabilities (Heylighen et al., 2013). For this purpose, Heylighen and her team analyzed how people use a space, which is also considered a participatory design approach (e.g., "Nørreport Station", n.d.; Jørgensen, 2022), by visiting a contemporary building, The Museum M building in Louvain, Belgium, with two user/experts, one of which is a wheelchair user and the other had visual impairment. After interviewing the designer firm, Stéphane Beel Architects, and analyzing their publications, it was learned that Museum M was designed by paying explicit attention to the experience of people with disabilities from the early design stages. However, while generally impressed by the quality of the venue, visitors found some

solutions problematic. For example, architects tried to propose a non-discriminatory entrance by combining stairs and ramps (see also Heylighen, 2012). Despite this equalitarian intention, visitors claimed that it was uncomfortable to use the ramp because of the non-continuous railings, and they feared stumbling down the stairs. Moreover, the white colors of the ramp and stairs made them hard to distinguish, and both visitors hesitated to use them independently. After the study, it was concluded that both the relationship between architecture and disability and the one between the human body and the space entail much more than accessibility guidelines, mathematical proportions, and functional dimensions. Thus, the participation of experts with experience in design was found beneficial and necessary.

To conclude, by these examples, it may be said that the guidance of people with disabilities can be useful to make designers and students gain insight into disabling spaces and disability experiences and eventually change the design customs toward universal/inclusive design, even though people with disabilities do not actively participate to the design decision process.

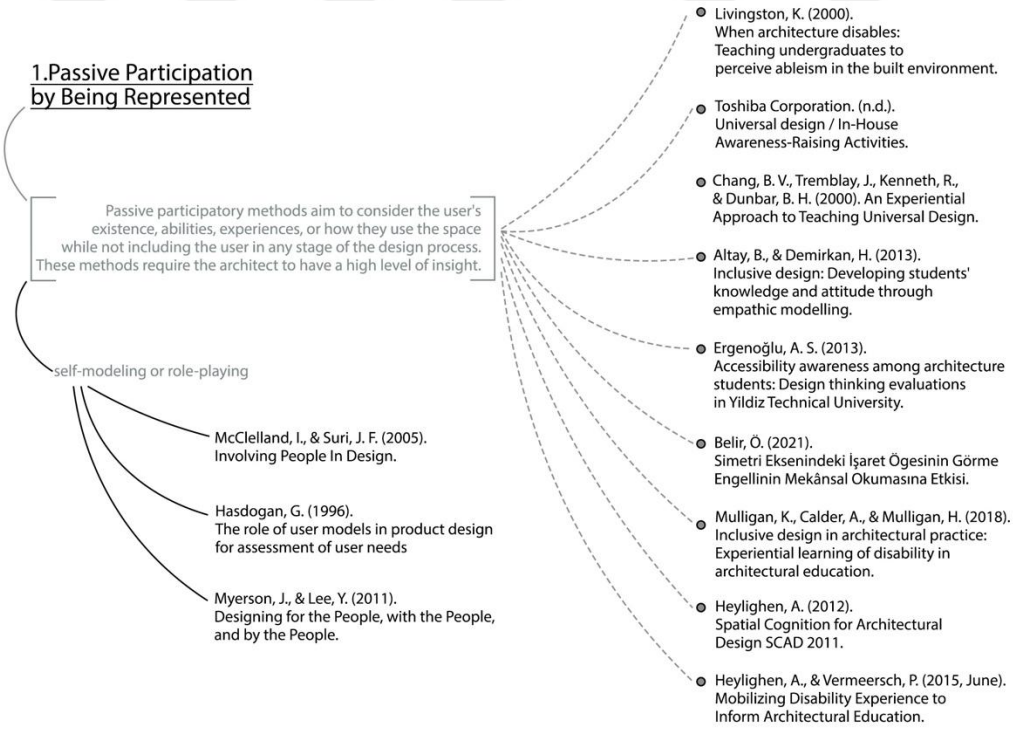


Figure 3.5 Map Summarizing Passive Participation Methods and Related Studies

3.2.2 Participation with Dialogue & Feedback / Focus-Groups

The role of the participatory approach in developing empathy required for universal design was highlighted in the last part. In their Open Letter to Architects, Cheryl Davis and Raymond Lifchez (1986, p.44) recommended that architects "talk" with people to understand the relationship between bodies with disabilities and the built environment and the social and psychological effects of that relationship on the individuals. In a similar vein, while discussing the primary purposes of PD, Sanoff (2000, p.10) pointed out that besides increasing user satisfaction, PD is also advantageous for the designer since it offers individual learning, gaining awareness, and reaching up-to-date pieces of information. For this reason, he (2000) emphasized the importance of being in dialogue with users/citizens to exchange knowledge for the desired community change and improvements.

Likewise, being in dialogue with possible future users in the design process suggested by RIBA to learn how to design for all. Since 1963, RIBA has provided design frameworks for architects covering the project stages from briefing to construction, which also evolves in time to respond to changing trends and needs. In the current version of the Plan of Work, RIBA (2020, p.32-34) indicated the "inclusive design strategy" as a crucial component of any project. And there were two main methods indicated in the RIBA framework for ID strategy. These were (a) to conduct Design Studies with the participation of the specialist consultants, users, and project stakeholders at the early stages of design and (b) to gather feedback from users with various needs on how the building is performing.

That is to say, the purpose of being in dialogue with users before and after the design process is seeking and reframing problems with experts by experience rather than designing solutions directly with the users (McGinley et al., 2022). It was believed that exchanging knowledge with dialogue provides a verbal design activity but does not dominate the architect's role (Luck & McDonnell, 2006). The most used methods of dialogue are (a) semi-structured interviews and discussions with users, in other words, "focus groups" (Sanoff, 2000, p.102), (b) workshop sessions, and (c) Post

Occupancy Evaluation (POE), however, design researchers designated various methods and used different combinations of them for fact-gathering from user/experts and increasing awareness among designers. Example studies are given in this part to clarify the semi-active participation methods.

To start with, Rachael Luck, a scholar at the University of Reading Department of Real Estate & Planning, has one of the scholars who carried out several studies about participatory design. She conducted a design project whose research team included Hans Haenlein and Keith Bright, referring to the "project briefing" stage in the RIBA Plan of Work (Luck et al., 2001). They tried to examine the effect of involving people with various abilities in the project briefing stage discussions and proposed a prototype methodology for briefing. For this purpose, a series of one-to-one semi-structured interviews with future users for a multi-functional building project design. Two interviewees with hearing impairments, one with mobility impairment, one with visual impairment, and two without any impairments participated in this project, and their different wants, needs, and expectations were tried to be revealed without letting participants be affected by other views (Luck, 2003). The data from the interviews showed that people with similar impairments could have conflicted ideas (Luck et al., 2001), so individual interviews are not an effective way to generalize user needs (Luck, 2003). This is why it was decided to continue the project with group discussions where participants could negotiate. After all, Luck (2001) claimed that those dialogue methods have successfully produced knowledge and insight and can help achieve egalitarian and non-discriminatory environments.

The project of exploring acoustic comfort at KU Leuven is another example of conversing with user experts about their spatial experiences before the design process to clear the problems that non-disabled designers may overlook. At KU Leuven, a neo-classic auditorium building designed in the 1780s, The Grote Aula hosts lectures and some music activities frequently. The plans of the university to renovate this historical monument and recorded complaints of students made the research team, consisting of Ann Heylighen, Monika Rychtarikova, and Gerrit Vermeir (2010), test the acoustic characteristics of the building with user/experts to propose points to

consider for the renovation process. In the scope of this study, six students with a hearing or visual impairment and representatives of the University of Elderly, whose spatial experience is directly related to acoustic quality, were interviewed to reveal the problems they faced in The Grote Aula. After discussing with user/experts, it was concluded that The Grote Aula's acoustic quality had been affected negatively by the 'strong resonance' or 'long reverberation' (2010, p.285). To solve this problem, researchers proposed interventions regarding material choices, tested different materials, and suggested using assistive technologies in the auditorium to support acoustic quality.

Design researchers have also promoted dialogue with users in design professions with different methods. An example of this is the DBA Inclusive Design Challenge, an annual design competition for creating inclusive solutions and involving users in the process in creative ways, organized by the Royal College of Art (RCA) Helen Hamlyn Centre (HHC) in collaboration with the Design Business Association (DBA) (Cassim, 2004). As a result of questioning how to educate and inspire designers about inclusive design and aiming to produce case studies and missing knowledge, RCA started the Challenge in 2000 as an open competition for professional designers (Lee & Cassim, 2009). In the Challenge, design teams are asked to focus on an area they chose under the theme given by RCA (i.e., Sedentary Lives, Dementia, Active Aging) and design service, product, or environment for mainstream users, not only for disabled people (Cassim, 2008b; RCA, 2008). In the design process, HHC provided text-based information, web links, and forums to allow the participating design teams to contact the critical users, who are not easy to make assumptions about by designers (Dong et al., 2005; Cassim, 2008b; Lee & Cassim, 2009). In this process, the design teams got inspiration from the users' life experiences, brainstormed to solve their problems, and let users evaluate their design ideas (Lee & Cassim, 2009). At the end of the Challenge, HHC evaluated both the resulting project and the user engagement method used by the design team to decide the winner (Cassim, 2004; Dong et al., 2005).

After the Challenge, even though some project teams claimed that the critical user forums could not be used in commercial projects because of a lack of time and budget, some teams used the findings of DBA to conduct user research in their commercial projects and participated in the Challenge more than once (Dong et al., 2005). Eventually, more and more design consultancies were interested in participating in the Challenge to gain experience in working with critical users (Dong et al., 2005), and the Challenge gained attention worldwide. Julia Cassim, the pioneer of the DBA Challenge, runs workshops about the Challenge and has started to introduce the Challenge to different countries, such as Hong Kong, Japan, Scandinavia, and Singapore (Cassim, 2008b; Cassim & Dong, 2015; RCA, 2008; RCA, 2009). To conclude, it can be said that the DBA Challenge became a successful example demonstrating how being in dialogue with users and learning from their needs and aspirations can be a powerful tool of innovation to design for all (Cassim, 2004). Moreover, in the later challenges, the role of the users has changed from advisors into design partners by empowering people with disabilities in design decisions (Cassim & Dong, 2015).

As said before, participants produced many designed projects, products, and services for the DBA challenge. Julia Cassim (2000-2008) documented those projects in an annual publication named *Challenge* (formerly *Innovate*) to provide exemplars of inclusive design for different disciplines (Cassim & Dong, 2015). One of the award-winner architectural projects, designed by JudgeGill for the dementia-themed 2008 Challenge, was Ormsthwaite House. The Ormsthwaite House is a concept project of modular care home designed for people with dementia after conducting briefing and evaluation sessions with a dementia expert, contacting carers and professionals in user forums provided by HHC, and consulting with the staff and residents of another care home. In the briefing sessions, designers found that traditional care homes are unsuitable for older people with dementia since their design is confusing, isolating, and reduces mobility. To solve these problems, a circular open plan, providing unrestricted movement by being easy to monitor, and a simple navigation system

with contrasting lines and color schemes, making residents identify their room without using signage, were designed (Cassim, 2008a).

The winning projects in the 3rd edition of The International Union of Architects (UIA) Friendly and Inclusive Spaces Awards can also exemplify how the participatory design methods of dialogue between designers and users can create inclusive environments (UIA, 2021). One of the projects is the Bamboo Playscape (Paraa, 2021), the medalist in the Public & Open spaces category, designed with children of different ages and abilities according to participatory design approaches. After finding out the children's needs and preferences through workshops, the design team asked children to choose two design proposals from 27 alternatives designed by different groups. The selected designs were mentored and supported to finalize, and the team constructed the playscape with various therapeutic exercises for differently-abled children. Another award-winning project is a research project named Support Ageing through Design conducted by Architectural Services Department, Hong Kong Special Administrative Region. The research team used a combination of different participatory methods to generate an elderly-friendly design guideline. Firstly, by conducting group discussions and brainstorming sessions, it was aimed to address and discuss the needs of the elderly. Secondly, the research team organized an aging simulation exercise and role-played the elderly by wearing special gear that reduced physical abilities and vision. Then, the team also walked through public facilities by pairing up with the elderly to interact with the users. In the last stage, the design guidelines were developed by conducting briefing sessions and being in dialogue with the elderly (Elderly-friendly Design Guidelines, 2019).

With the idea that education's role is critical to "changing attitudes on values" of future architects (Jenkins, 2010a, p.5), researchers have also used participation methods with dialogue in design schools. For instance, at the University of California, professors of architecture Núbia Bernardi and Doris C.C.K. Kowaltowski (2010) conducted a design course focusing on practicing Universal Design. In this course, to generate sensitivity toward the relationship between users and the built environment in students, Bernardi & Kowaltowski (2010) used role-playing

exercises at first, similar to the examples given above. However, they noticed that those exercises are insufficient to understand the disability experience. To enhance the empathy exercises, they invited people with visual impairments to the course to evaluate the design proposals from the user perspective. The evaluation and feedback session was beneficial in discussing the needs of people with visual impairment. Such as, it was seen that after the role-playing exercise, students tended to create flexible designs and tried to remove any obstacle. However, during the feedback, the participators said that people with visual impairments need permanent architectural elements as references for wayfinding. At the end of the semester, Bernardi & Kowaltowski (2010) claimed that the presence of users with disabilities heightened students' awareness of such users' preferences and needs.

Another educational project was conducted at Hasselt University by following the idea that "besides understanding users' needs and expectations, the ways in which users perceive and experience the environment contain valuable knowledge for designers" (Ielegems et al., 2021, p.102). However, expressing perceptions and experiences is more challenging than communicating needs and problems. For this reason, researchers designated a one semester-long project named 'Light up for *all*' by combining different participation methods with various users. Second-year architecture students, who had no prior knowledge about UD, were asked to design a light switch and socket usable by all people to the greatest extent possible. The project started with two workshops with the participation of user/experts to enable direct contact. After gaining some insight and knowledge on the experiences of people with disabilities, students prepared their design proposals and had the chance to get feedback from user/experts on models. It was indicated that students found it more beneficial to take feedback from the prototypes since user/experts had no design background to communicate on drawings. Moreover, they thought it was valuable and helpful to hear the personal stories of people with disabilities to understand the impact of design on the lives of people. For instance, user/experts with visual impairments said that even though they do not use the light, they wish to know whether the lights are on or off because they find it bothersome being the one

sitting in the dark when others enter the room. This was not something that designers and students would quickly notice with empathy, instead, it was a situation that would require communicating with someone with direct experience to understand.

In the second part of this study, students also got feedback from the care center residents on the final prototype approved by the user/experts of the first part. However, in the second part, students wanted to test the intuitive use of the user/experts. It was seen that although the user/experts, who received information about the design, said that the design was easy to use, the users who encountered the design for the first time did not know how to use it and tried to push the turning button. For this reason, the students concluded that observing behaviors and examining verbal opinions are both necessary to gain accurate information about users. All in all, architecture students valued interacting with experts by experience and learned practical lessons, even though this was a product design project.

In summary, participation studies such as interviews, discussions, workshops held before starting the design, and methods such as evaluation, feedback, and choosing among alternatives after the designing process provide the necessary information to make a more inclusive design while not dominating the role of the architect. On the other hand, as seen in the examples, this participatory process, which consists of obtaining information, designing, getting feedback, and redesigning when needed, may cause time-related problems and force the user's ideas to be directed by the architect. In consideration of these, different participation strategies increase the effect of the user on the design proposed by researchers. The next part focuses on those strategies.

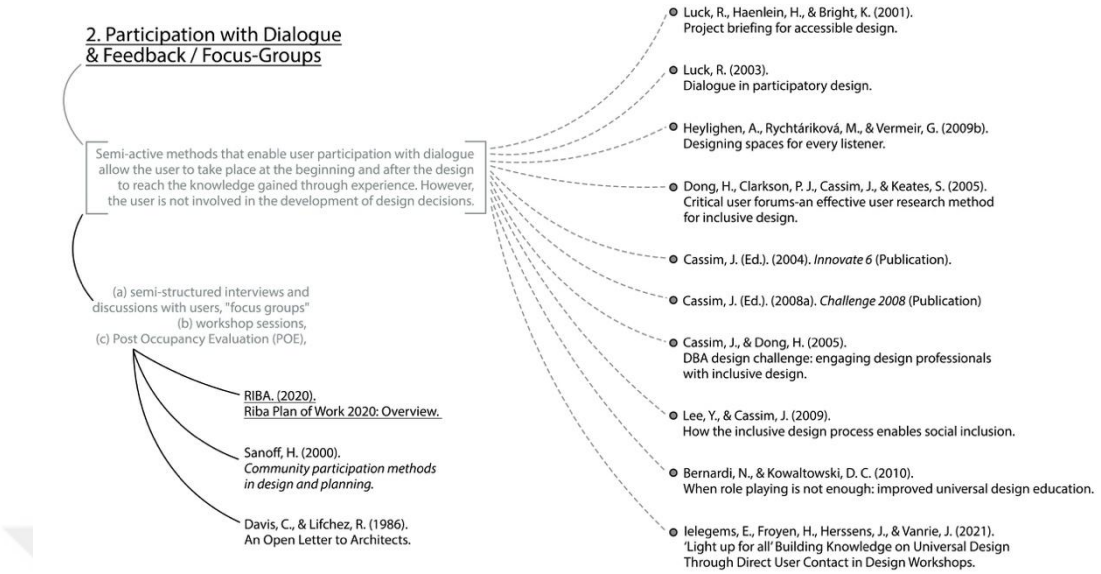


Figure 3.6 Map Summarizing Semi-Active Participation Methods and Related Studies

3.2.3 Active Participation to Design Team as Consultants / Co-Design

Although the benefits of designing by obtaining information and comments from user/experts to reach universal design have a vast place in architectural discussions, this participatory approach has also been criticized. Examples, such as resorting to the ideas of user experts when all design plans had already been ready (Leaman, 1981), resulted in comments like participatory design approaches were a reflection of architectural populism (Albrecht, 1988; see also Arın, 2017). To avoid misapplication of participation, scholars demanded the right of full consultation, in other words, "cooperation" (Davis, 1981, p.34; Leaman, 1981). Their idea was that beyond problem-seeking, people with disabilities could offer assistance in producing solutions (Davis, 1981).

One of the projects was undertaken at the Canadian Institute of Barrier Free Design (CIBFD) / Universal Design Institute (1997) with the idea that the ones experiencing disability should take place in the design process as consultants. The project's aims were (a) training users/experts in universal design since not everyone experiencing

disabilities has the proper knowledge of all access and design issues and (b) eventually generating new business spaces for disabled people. After several workshops, the participants were hired for several municipal projects in Winnipeg, Canada, and showed how users/experts could contribute to the universal design process (Ringaert, 2001).

One of the pioneers of participatory design, Sanoff (2000, p.150-155), also led a project in which people with disabilities actively took place in the design decisions. The project was the renovation of the master plans of Minnesota Academies for the Blind and the Deaf, which the Adams Group and Henry Sanoff conducted in 1997. For the projects, a series of participatory activities were applied separately for the two campuses. Both projects started with site walkthrough exercises, followed by open-ended discussions with students. Students studied the plans and explained their desires and needs during those exercises. The campus design for the Academy for the Deaf continued with interviews with the Academy's staff, who were asked to name the two most critical problems they saw in the existing campus. The design proposal was prepared according to those interviews. In the Academy for the Blind project, it was preferred to generate groups of five among the staff and let the groups design their proposals with plan drawings. Afterward, the proposals were examined by the design team, and the common ideas of designing a new entrance and placing a weather-protected connection building on the campus were used in the final project. In the end, campus improvement projects were prepared according to the real users' needs.

Another example of designing with the consultation of user/experts was seen in Imrie (2000)'s study, in which he compared the design processes of two shopping malls. While one design group, TeamCo, aimed to end up with a mall providing a non-discriminatory experience, the other group, SouthCos, thought it was enough to do the bare minimum given by regulations. Both design teams were provided an access group to approve their design decisions. The SouthCos chose not to engage with the access groups blaming the strict timeframe of the design process. On the other hand, the TeamCo established strategic consultative meetings regularly throughout the

design development process, and those meetings continued for the mall's management even after the design was completed. According to Imrie (2000), actively seeking advice, keeping the access group informed in every update, and listening to and interpreting their ideas made TeamCo illustrate the possibilities of designing beyond regulations.

The example studies at KU Leuven were mentioned in the previous participation methods. The co-designing strategy was also tested at this university by the participatory design scholars Vermeersch, Schijlen, and Heylighen (2018). For this purpose, researchers selected the redesign project of the Van Abbe Museum in Eindhoven to set up co-design workshops. By aiming to introduce the expertise of both people living with an impairment and architects into the design process in a balanced way, a series of workshop sessions were designated. At first, three sets of workshops took place for groups consisting of people with similar impairments, hearing, visual and mobility, and an architect. Each group proposed a concept project represented with models and sketches after the workshops led by the architects. In the second session, a representative of each group and architects came together to present the concept projects, brainstorm, combine the design ideas, and have a concrete design proposal. Taking all the inputs seriously, letting user/experts make their design moves, and holding the workshops before making any design decision resulted in designing an equalitarian museum experience. To illustrate, it was aimed to offer all visitors a similar lower viewpoint to experience art and, at the same time, to provide opportunities for communication to all, involving people using sign language, by placing seating alcoves that are arranged slightly looking at each other in front of artworks.

Another study of designing with an active participation process was conducted in Bursa, Turkey. Sebla Arın and Ahsen Özsoy (2015; 2021; see also Arın, 2014) supported the idea that designers and authorities should let children and younger adults represent their ideas for the built environment they live in to have a genuine process of participatory design. With that philosophy, Arın (2017) designated a co-design project in which thirty differently abled children aged 8-14 played an active

role. For this project, which was named "Oyun Engel Tanımaz", participants were first given lectures on the built environment, spatial rights, and basic design. Afterward, with a series of workshops, they were asked to create new play scenarios and design a children's playground for the strict where they live and study. Moreover, by sticking to the children's design ideas, the playground was constructed in Nilüfer, Bursa, within the project's scope. Children were also allowed to observe and take place in the construction phase to arouse environmental consciousness. Being contributed by universities, municipalities, and non-governmental organizations and using the ideas that children came up with in the design process made this project a successful example of cooperation.

As in the previous methods of participation, this method is also used by some scholars in design education. One of the leading actors of this method is Raymond Lifchez, a professor of architecture and city & regional planning at the University of California-Berkeley. He related disability problems to ignorance (Lifchez & Winslow, 1979) and believed that the frequent presence of people with disabilities in design studios is one of the most effective ways of addressing the issue of physical accessibility. With this understanding, he carried out a course on designing inclusive environments at Berkeley which involved elderly and disabled people (Lifchez, 1978), and at the end of the semester, it was seen that almost the entire class found it helpful to have consultants in the project teams, got the sense of the complexity and variety of user needs, and generated a positive attitude toward people with disabilities (see also Sarkissian, 1986a; 1986b). After these positive results, Lifchez tried to raise the attention given to this teaching method and invited five other architecture schools in North America to have consultants in their studios in the scope of the project named Exxon in 1979 (Lifchez, 1981). The idea behind Exxon was that inclusive design involves both accessibility issues and sociological aspects. After the positive results of the Exxon project, Lifchez (1981, p.23) claimed that "physical disability and architectural access are meaningless unless taught within a context of human experience" and suggested that all other schools of architecture try this method.

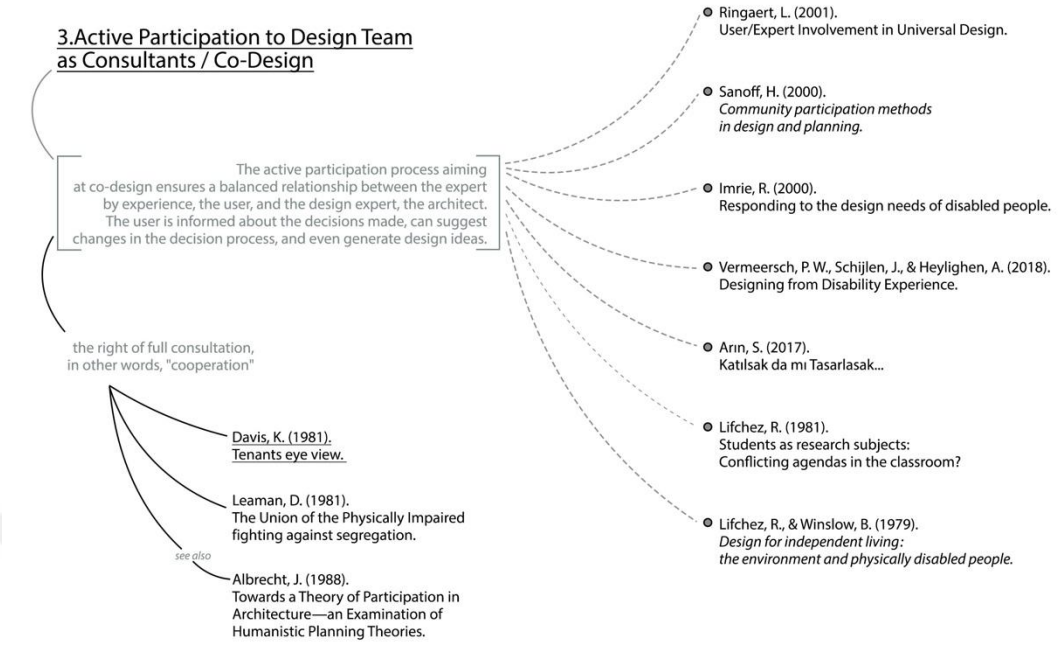


Figure 3.7 Map Summarizing Active Participation Methods and Related Studies

In conclusion, even though the participatory methods do not have strict boundaries separating them, the given titles of participation strategies can be summarized as follows:

1. *Passive participatory methods* aim to consider the user's existence, abilities, experiences, or how they use the space while not including the user in any stage of the design process. These methods require the architect to have a high level of insight.
2. *Semi-active methods* that enable user *participation with dialogue* allow the user to take place at the beginning and after the design to reach the knowledge gained through experience. However, the user is not involved in the development of design decisions.
3. *The active participation* process aiming at *co-design* ensures a balanced relationship between the expert by experience, the user, and the design expert, the architect. The user is informed about the decisions made, can suggest changes in the decision process, and even generate design ideas.

Deciding which method of involving users is the most beneficial or reliable in a specific design context may require further critical studies (McClelland & Suri, 2005). Involving people with disabilities in the design process as consultants seem to be the solution that provides the most active, direct, and effective participation (Lifchez, & Winslow, 1979, p.16). However, the difficulties mentioned in the example studies should be considered to review participatory approaches thoroughly and to make a conclusion.

The researchers highlighted five main topics related to involving differently-abled partners in the design process. First of all, it should be noted that architects cannot completely count on the design abilities of consultants (Davis & Lifchez, 1986; Ielegems et al., 2021). Expressing and understanding abstract design ideas requires expertise and technical knowledge that users do not necessarily have (Hall & Imrie, 1999). Moreover, coping with the strict time frame demanded in the design process may be hard for an outsider, which can also put the architect in a difficult position (Imrie, 2000). In addition, consultants or other participants may doubt themselves and prevent making contact or sharing their ideas not to disrupt design processes (Sarkissian, 1986b). Although some studies have included trained participators, consultants with design backgrounds would be hard to find, and training user/experts would need extensive projects with time and budget. Secondly, trained or not, consultants should not be expected to participate design process on an entirely volunteer basis (Mason, 1992). In some studies, participants asked for a financial return for their time and wanted to share the intellectual property of the design outcome they contributed (Vermeersch et al., 2018). Moreover, in some studies, it was seen that participants' ideas were more likely to be ignored by the architects when there was no financial contract (Hall & Imrie, 1999). The third topic mentioned by the researchers emphasizes the role of the architect's skills in the participatory design process. Rachael Luck (2007)'s study illustrated that the abilities to lead a participatory process properly, like asking the right questions or interpreting consultants' ideas, are gained by experience and practice. Therefore, scholars have claimed that the participatory design approach would necessitate new learning

methods and curricula for design professions (Sanders & Stappers, 2008). Otherwise, misapplied user participation can be seen (Davis & Lifchez, 1986) and waste time and budget. The fourth topic to be concerned with is also related to resources. Even if all of these situations are resolved, the customer's reluctance to spend their money on the participatory design process can become an obstacle. Hence designing inclusive environments with the participatory approach requires educated and aware clients and also being supported by regulations to convince clients (Hall & Imrie, 1999). And lastly, involving people with disabilities as the participants in the design process but not considering the possibility of disabled people being *the designer* can be criticized for reinforcing the "other" and "them" status (Mason, 1992). This secondary role does not truly align with the social model and human rights-based approach. The feminist scholar Aimi Hamraie (2013, Theorizing Value-Explicit Design, para. 11) points out that situation in the Universal Design Perspective by saying:

> User involvement is, nonetheless, only one piece of the UD puzzle; that is, UD requires *more than* additional knowledge about disabled people and bodies (in which case designers may come to treat misfitting bodies as *no more than* objects of knowledge for designers). UD must also address the structural conditions that prevent marginalized people from becoming professional designers or having access to decision-making in design processes.

Following this idea, contributions of the differently-abled architects to the architectural profession are examined in the rest of this chapter.

3.3 The Contributions of Differently-Abled Architects in Literature

In their book, Lifchez and Winslow (1979) recount a conversation with Irving Zola, an activist, and scholar who specialized in medical sociology and disability rights.

According to what they reported, Zola commented on Lifchez's studies of increasing empathy in design students by involving people with disabilities in the studio and said that a designer could understand disability in all its aspects and develop empathy only by witnessing at least one full day of a disabled person. Although it is unlikely for every designer to have this intense observation, Lifchez & Winslow (1979) agreed with Zola's opinion since designers who have emphatic understanding are mostly close witnesses of a disabled person's life. With a parallel understanding, while discussing the different levels of attention given to accessibility in design schools, Marta Bordas Eddy (2017a), who is also an architect with a disability, stated that the personal commitment and empathy level of instructors and students form those differences. According to Eddy, the ones engaging in teaching or learning accessibility mostly have a personal relation to the topic, such as having a disabled family member or being disabled. Defending a similar point of view, Ruth Murrow (2001), professor of biological architecture at New Castle University, has suggested encouraging people from various backgrounds and abilities to study architecture to reinforce the understanding between the architect and the end user and to achieve a paradigm shift toward inclusive design.

Scholars sharing those ideas tried to support their discussion by giving place to studies of architects with disabilities and their contribution to the spatial rights of disabled people. As excepted, Ronald Mace, the pioneer of the Universal Design paradigm, was one of the names mentioned in those discussions (e.g., Bordas Eddy, 2017a). After contracting polio at the age of 9, Mace became a wheelchair user in the inaccessible society of the 1950s. He was assisted by his mother during his education, he created his own solutions to cope with his environment, such as designing a device that enabled him to squeeze his wheelchair and use inaccessible bathrooms, and he lived in a mobile home since the buildings of the North Carolina State University was not accessible during that time. After graduating, Mace used the insight and knowledge that comes with living with a disability to analyze ignorance in architecture resulting from the invisibility of disabled people in society, to help design the first accessibility code in the USA, and to establish Universal

Design (Hamraie, 2017). Giving a considerable place in Mace's bibliography in his book, Aimi Hamraie (2017, p.17) defined Mace as an "epistemic activist" who "chose scientific research, architectural education, accessibility code development, disability policy" to fight with disabling culture.

Similarly, an architect with diverse abilities, Şükrü Sürmen has pioneered many studies on disability and spatial rights in Turkey. While he was an architecture student at İstanbul Technical University (İTU), his body was paralyzed after a car accident (İstanbul Üniversitesi, n.d.). After a period of rehabilitation, Sürmen attempted to turn back to his education several times. However, the medical model understanding was mainstream in Turkey during those years, and according to Sürmen (2007, p.50), "even going out was to endure a significant psychological pressure". Even so, Sürmen completed his undergraduate education at İTU in 1973. Sürmen directed his experiential knowledge to accessibility, conducted research studies in Germany, and then taught the first architectural course on the design for people with disabilities and the elderly in Turkey at İTÜ (İstanbul Üniversitesi, n.d.). To pave the way for accessibility in Turkey, Sürmen compiled standards and measurements in a handbook (1995), wrote a number of articles on design for the elderly (2000), and prepared illustrations of accessibility standards (2004). Sürmen (2004) even wrote a prescription on how to construct accessible toilets easily to support inclusive design. It can be said that, like Ron Mace, Şükrü Sürmen was also an "epistemic activist".

However, limiting the insight of architects with diverse abilities to accessible design would not be accurate. It was argued by scholars that differently-abled architects might create a richer and wider pool of talent and creativity in the architectural profession as a result of varying experiences and perceptions (De Graft-Johnson et al., 2015). To exemplify the creative design abilities of differently architects, the studies on the practices of three different architects are given a place in the rest of this chapter.

3.3.1 Carlos Pereira

Carlos Mourão Pereira is an architect, researcher, and tutor best known for his studies on the multi-sensoriality of the space. After getting his bachelor's and Ph.D. degrees from the University of Lisbon, from 1991 to 2005, Pereira practiced architecture in different firms in Lisbon, Zürich, and Genoa, where he worked with Renzo Piano, and he won several prizes. Moreover, since 2003, he has taught design studios and attended workshops in different universities, including Trakya University, Turkey (Carlos Mourão Pereira, n.d.).

Pereira has always given attention to the ocular-centric characteristics of the architectural profession and the effect of non-visual senses in place. However, after 2006, when his vision was impaired, he interpreted being blind as an opportunity and expanded his knowledge about multi-sensorial experiences (Vermeersch & Heylighen, 2013). Since then, Pereira has maintained his architectural activities and has tried to challenge design practices, from site analysis to representation, with the new insight he gained (Vermeersch & Heylighen, 2012).

In the interview that Didem Kan Kılıç (2016) conducted to find out the wayfinding strategies of visually impaired people, Pereira stated that the smell and the haptic quality of the built environment are essential for him to experience the city. This way of experiencing the space affected how Pereira documents the building sites. According to the personal conversations, lectures, and interviews that Ann Heylighen (2012) quoted, Pereira, visits the sites before starting design and touches everything. Moreover, he records the environment's sounds to listen and work on afterward. Similarly, during the design process, Pereira uses unusual ways to communicate his ideas instead of photographs and sketches. For instance, he extensively uses gestures and supports his designs with physical models made with clay, cardboard, or Legos (Heylighen, 2012; Pereira et al., 2017). Furthermore, Pereira adds texts, sounds, and complex materials to the physical models of his designs to be experienced with all senses. For example, Pereira produced a wooden model filled with scented water and displayed it with a sound record from the design

site for the International Architectural Model Festival (Vermeersch & Heylighen, 2012). On the other hand, the architectural quality of Pereira's monochrome models proves the idea that Pereira's attention to non-visual experiences does not make his works deprived of visual aesthetics (Heylighen, 2011; Vermeersch & Heylighen, 2012).

A similar philosophy of designing for all senses can be seen in the installations Pereira developed for various waterfronts. After realizing that enjoying the coastline alone is dangerous for a blind person, Pereira turned his design focus to sea bathing facilities where all people can enjoy the water, including pregnant women, disabled people, children, and the elderly (Heylighen, 2011; Vermeersch & Heylighen, 2012). He created design proposals for Paimogo Beach in Lourinhã/Portugal, the Rosignano Marittimo beach on the coast of Livorno/Italy, the waterfalls of Schaffhausen/Switzerland, and the river Krki in Slovenia. These projects, which are shaped according to the topography of each site with the materials suitable for each region, have a common goal of providing culture and leisure for all people (Carlos Mourao Periera, Archello, n.d.). By designing with ramps controlling the slope and handrails tracing the ramps at different levels, Pereira created a safe and accessible environment (Vermeersch & Heylighen, 2012). Those ramps direct the users into the swimming basins next to which fisheries were located. With the colors and textures of sea creatures, the smell and sound of water, and the temperature of the wind controlled and directed by walls, Pereira aimed to provide a design that stimulates the whole body of any user (Heylighen, 2011; 2012; Vermeersch & Heylighen, 2012).

Carlos Pereira continues his research focusing on the user experience with Teresa Heitor and Ann Heylighen (Carlos Mourão Pereira, n.d.). Lately, they have been conducting interviews with users on thermal comfort in cities (Pereira et al., 2019) and beaches (Pereira et al., 2022). The results of those studies made the research team propose inclusive shadow shelters and loggia spaces to be constructed to protect users from the effects of climate change and to lower the health risks. It is also seen in the discussions that researchers adapted an inclusive understanding in those

studies by considering the needs of pregnant women, people with young children, and people with sensual impairments (Pereira et al., 2022). Moreover, it was foreseen that the passive cooling effect of those shelters might reduce the energy consumption for temperature regulation (Pereira et al., 2019).

After discussing Pereira's design methods, philosophies, and research studies, it can be concluded that with the insight he gained from being visually impaired, he developed a design understanding that promotes inclusive, sustainable, safe and multi-sensorial environments. In addition, he tries to teach that understanding to future architects.

3.3.2 Chris Downey

Chris Downey, an architect, planner, consultant, and lecturer, is another pioneer name in architecture for visually impaired people. Downey was featured on many media platforms (e.g., Hixson, 2016; Stahl, 2019), gave international speeches, including a Ted Talk ("Chris Downey", 2013), and was mentioned in scholarly studies for his achievements and life story (e.g., Kılıç, 2016). To put it briefly, after practicing as an architect for twenty years, Downey underwent brain tumour surgery which caused a total loss of sight and sense of smell (Slatin, 2011). After the surgery, he got specialized training and started to continue his career within only months. With his career consisting of being a sighted architect for years and then being an architect without sight for approximately fifteen years, Downey has gained a piece of unique knowledge of spatial experience. That knowledge made Downey a critical name in design for all senses and universal design. Correspondingly, Downey regards his impairment as a strength and defines himself as an architect without sight but with vision (A man with a vision, 2014).

After turning back to practicing architecture, Downey's had an opportunity to use his experiential knowledge in a project, where the difference between the spatial experience of users and designers had become a problem, Polytrauma and Blind Rehabilitation Center for the Department of Veterans Affairs in Palo Alto (Slatin,

2011). Focusing on the multi-sensorial human experience, the Rehabilitation Center is designed in a way to provide navigation with tile colors and textures in the pavement and flooring, to reinforce wayfinding with aesthetic and tactile design features such as wood panels in elevator lobbies, to help people with photo-sensitivity by giving extra care to transition from natural light to artificial light, to increase the easiness of orientation by placing acoustical vaults on ceilings and thus to respect all visitors ("Veterans affairs Palo Alto", n.d.). The features of providing equity by design and focusing on the healing effect of the space made the project win the 2019 Healthcare Design Award given by the American Institute of Architects ("The U.S. Department of the Veterans", n.d.).

Following his abilities that came to light in that project, Downey rotated his professional interest to the projects for people with disabilities, especially visually impaired people. To be able to design in a profession that was generally practiced with visual tools, Downey developed his own strategies and materials by saying that "architecture is first and foremost a creative endeavor" (Slatin, 2011, p.12). He designs with wax tools that can be easily shaped and embossed plans, which are the tactile versions of drawings (Slatin, 2011; Heylighen, 2012). Interpreting the space with a different priority and bias in the brain (see also Downey, 2013), Downey believes that designing for impaired people would result in better environments and cities ("Chris Downey", 2013).

UC Berkeley, where Ray Lifchez had started a practice of involving differently-abled people in the design studio, followed Downey's perspective and recruited him to lead a graduate design studio as "the inaugural Lifchez professor of Practice in Social Justice", a title given to honor Lifchez's legacy ("Christopher V. Downey", 2022). In his studio, named "Confronting Our Blind Spots", Downey aims to teach the philosophies of advocacy, justice, and accessibility as opportunities for creativity. He tries to emphasize thinking beyond coping with codes and beyond the stigmas about people with disabilities, such as disabled people belong, what they can do, etc. In spring 2022, students were asked to design an inclusive boathouse where all people can practice sports activities equally for Downey's studio, and they produced

3D printed braille architectural drawings. By designing for and by universal thinking, students claimed that the way they think about design entirely changed after this course (Snowden, 2022).

While serving as a professor, Downey has also continued his professional career as both a consultant and a designer in his own firm, *Architecture for the Blind*. One of the featured designs that he contributed is the headquarter of the Lighthouse for the Blind and Visually Impaired in San Francisco. The Lighthouse is an organization of blindness pride that sets up workshops, camp activities, science, and map classes, offers training on accessible technology, conducts community projects, and produces tactile maps (Getting Started, 2019). Chris Downey has taken part in the LightHouse since 2009 and has also worked as Board President (Lighthouse, 2016). The headquarter of this organization was designed to be functional and aesthetic for all, including both visually impaired and sighted people, by a team led by Mark Cavegnero Associates. The project was completed in 2016 and consists of exam and training rooms, a retail store, tech labs, a training kitchen, offices, conference rooms, and accommodation facilities, occupying three floors of a high-rise building (Mark Cavegnero Associates Architects, 2019).

It was aimed to provide an aesthetic experience of space for visually impaired people in this project, and every element was designed accordingly (LightHouse, 2016). Firstly, a central stair was designed to connect three floors of the headquarter, obtaining a quality skylight. Despite the mainstream idea that light would not make a difference in the experience of blind users, most visually impaired people perceive the contrast between daylight and shadow and use it to navigate and follow time. That experiential knowledge was used in the design of the stairs. Moreover, stairs were designed wide enough to be used by two people and one service dog (Stalin, 2016). Another feature of the stairs is the user-friendliness of the materials. The handrails and the noising profiles were designed with a process in which mock-up models were printed in 3D, and both the material quality and design were tested (Mark Cavegnero Associates Architects, 2019). Like in the previous project of the Rehabilitation Center, acoustic quality was also used to help with wayfinding. For

that purpose, designers worked with an acoustic designer (LightHouse, 2016); the sounds of the space were digitally animated, and it was tried to achieve a warm and enlivened space experience without being overwhelming (Stalin, 2016). It can be concluded that with the contribution of Chris Downey, a multi-sensory experience was designed to equate the space for all.

In addition to these, Downey gave consultancy to the Salesforce Transit Center project in San Francisco. For this project, a walkway model was constructed to test the tactile surfaces and find the best solutions that work for all, including visually impaired people, people who use a wheelchair, crutches, service dogs, or canes (Bernstein, 2021). He worked in collaboration with the architectural firm HOK as well. In the projects of UPMC Vision and Rehabilitation Tower at UPMC Mercy and Waterloo Eye Institute, he advises HOK on equality, inclusiveness, and wayfinding strategies (HOK, 2021a; 2021b). Downey is also one of the members and the chair of the Executive Committee of the California Commission on Disability Access (CCDA, n.d.).

3.3.3 Marta Bordas Eddy

Marta Bordas Eddy is a practicing architect, researcher, and instructor who is also a wheelchair user. After the car accident that caused Bordas Eddy (2017b) to have a spinal cord injury, she began to notice that her disability was actually the result of architectural barriers and decided to become an architect to solve them. However, during her education, she faced many difficulties resulting from "the ignorance of, distance from and taboos towards people with disabilities" (2017b, p.44). The inaccessibility of buildings, the misuse of parking spots for people with disabilities, the specialized design like platform lifts pointing out her bodily state, the lack of accessible seatings in classrooms, and many other disabling barriers taking place in two faculty buildings where she got educated, shaped the mindset of her about disability and accessibility.

According to Bordas Eddy (2017a), there is an endless loop in the built environment behind the disablement of people. The loop starts with a lack of knowledge about the needs of people with disabilities, and that results in the wrong design, which consists of architectural barriers. Barriers prevent people with disabilities from participating in society and cause invisibility and isolation. The invisibility or the lack of disabled users reinforces the misjudgments and prejudices about people with disabilities, and those stigmas result in designers seeing no need to produce knowledge about people who will not use the designed product. Consequently, the loop recreates itself (see also Liebergesell et al., 2018).

Two ideas of Marta Bordas Eddy supported seem to have the potential of breaking the loop. Firstly, Bordas Eddy (2017b) mentioned that after she had opened the way to studying architecture in her university, more people with disabilities started their education in the same institution. This situation resulted in the building and managers feeling the necessity to solve the accessibility problems, and the barriers she had experienced were removed. Secondly, to prevent ignorance or taboos about accessible design, she suggests "unnoticed accessibility", which is being accessible without looking "for the disabled" (2017b, p.47). One example of a design project with unnoticed accessibility is Bordas Eddy's house, designed for and by herself (Bordas Eddy, 2017b; Liebergesell et al., 2018). Liebergesell and others (2018), studied the design of Bordas Eddy's house by analyzing design decisions and conducting interviews with her, her boyfriend, who also lives in the same place, and her sister, an interior designer working with Bordas Eddy. According to that study, having an impaired body and being an architect enables Bordas Eddy to observe barriers easily and produce solutions simultaneously. She claims that solving accessibility problems would provide a comfortable and safe environment for everyone; however, designers should give balanced attention to aesthetic quality to promote the use of those solutions. The qualities of her design achieved by the location of foreseen turning points, the lift working as an unboxed elevator, and the space freed from obstacles made her house usable for Marta and her non-disabled life partner while not looking for the disabled.

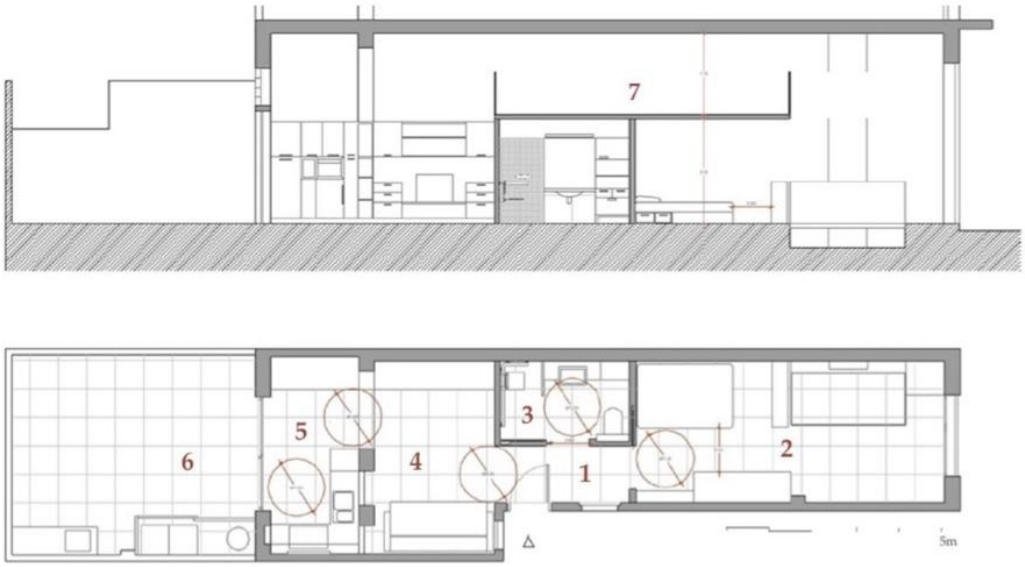


Figure 3.8 Cross Section and Floor Plan of Marta Bordas Eddy's House. (1) entrance hallway; (2) bedroom; (3) bathroom; (4) living room; (5) kitchen; (6) patio; (7) mezzanine. (Liebergesell et al., 2018, p.10). *Used Under Creative Commons CC-BY*



Figure 3.9 Photographs from Marta Bordas Eddy's House Showing the Design of the Platform and the Kitchen. (Liebergesel et al., 2018, p.11). Used Under Creative Commons CC-BY License

After discussing the contribution of Ron Mace and Şükrü Sürmen to the accessible design literature and viewing the projects and design understandings of Carlos Pereira, Chris Downey, and Marta Bordas Eddy, it can be concluded that the unique perspective generated by the combination of design knowledge and disability experience may result in improvements in the architectural profession. The facts that

accessibility standards rely upon the studies of architects with disabilities, that architects with visual impairments challenged the ocular-centric characteristics of the architectural profession, that diversely-abled architects also engage with design education, and that aesthetic qualities stimulating the whole body of all users were aimed to have by the architects with diverse abilities might support the idea of having diversity in the profession would result in a shift in design understanding prevailing architecture.

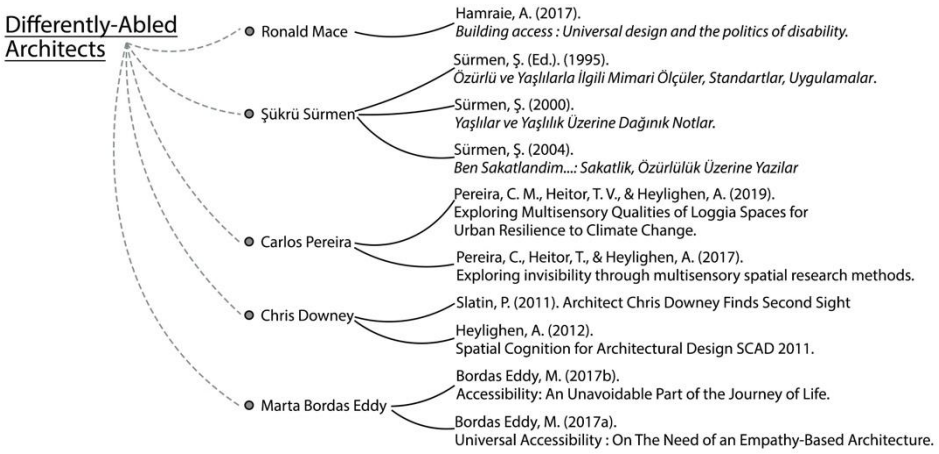


Figure 3.10 Map of Differently-Abled Architects

CHAPTER 4

DISCUSSIONS AND CONCLUSION

With the development of the Social Model, the definition of disability changed from a personal tragedy to a problem that occurred because of the mis-organization in society (Oliver, 1990). According to the social model, the barriers in the social environment result in unequal opportunities and prevent people with impairments from participating in society fully and living independently. With this new understanding, disability rights advocates supported the idea that disabling barriers should be defined and removed for the liberation of all people (Shakespeare, 2010). The inaccessible built environment is one of the most crucial barriers that people with impairments face in disabling societies (WHO, 2011).

There were some attempts to remove physical barriers in the built environment, one of which is establishing legislation and standards. However, it was observed that those standards could not be enough to achieve accessibility because they offered add-on solutions to designs and were seen as restrictions to creativity and aesthetic by designers. The ongoing construction of disabling environments despite standards resulted in designers and scholars developing new paradigms to bring a solution and make all design products able to be used by all users. Those paradigms can be listed as Universal Design in the US and Japan (Story, 1988; Hamraie, 2016; 2017), Inclusive Design in the UK (Clarkson et al., 2003), and Design for All in Europe. However, even though scholars defined the principles of UD and the stages of ID to make them more achievable in practice, designing for all abilities has not been a mainstream idea in architectural design yet (Imrie, 2003). According to several scholars, increasing the diversity of practitioners in the architectural profession may ease and accelerate the process of the paradigm shift toward a more inclusive approach (Lifchez, 1986; Murrow, 2001; De Graft-Johnson et al., 2005; Vermeersch

et al., 2012; Manley et al., 2011; Manley & De Graft-Johnson, 2013). This idea shaped the research questions of this thesis.

In order to research the possibility and necessity of participation of people with disabilities or, in most preferable phrase for this study, different abilities; the questions (1) what are the reasons and goals for the idea that people with disabilities should participate in architecture, (2) what point of view should be used to make a shift in the architectural profession to achieve active participation of people with disabilities, and (3) what contributions have been made by people with disabilities to the profession of architecture before were asked. To find the answers of those questions, a contextual reading of different pieces of scholarship concerning disability, society, and architecture was provided. The main goal of this reading was to find connections and parallelisms between different fields that can be used to answer the questions mentioned above.

In this scope; different models defining disability, the development of the Social Model, internal debates evolving the Social Model, the Social Constructive and Feminist Approaches to Disability, the practices of mis-organization in society resulting in disability, and the response of the disability movement to those practices, the philosophy shaping the paradigms of designing for all abilities, the Participatory Design Approach and the works and studies of five architects with different abilities were studied[3]. The main common grounds and parallelisms found in those fields, which answer the research questions in a holistic approach, can be summarized as follows:

i. The Agents of the Change

As discussed in the medical model, disability and impairment were considered synonymous in society. In this model, the individuals carried the responsibility of disability, and they were seen as people needing cures and rehabilitation. In response

[3] Please see Appendix E.

to the inequalities that the Medical Model offered, the Social Model of disability was established. The social model owed its strength to the active involvement of sociologists with disabilities and the organizations controlled by people with disabilities in its development process. Eventually, the efforts of people with disabilities forced the authorities to change their definition and accept that disability is not a misfortune but a result of society's mis-organization. It can be said that people experiencing oppression were the agents of change in society.

In a parallel manner, another minority group caused a change in society and the architectural profession. Similarly to the struggle of people with disabilities, women have faced discrimination, inequalities, and oppression which also affected the spatial rights of female users. In architectural environments, women were not represented, and their needs were not considered. In response to this situation, the feminist movement organized direct actions, and women's rights advocates supported the idea of having female architects. After the increase in the number of female architects, it was seen that the female body was beginning to be represented, and women were considered to be equal users, as was needed. It can be said that women themselves became the agents of change in architecture.

With the similarities seen in those events, an analogy can be made between both people with disabilities and women, and equating disability to impairment and equating barrier-free design to complying standards. Following these analogies, it can be said that the change towards inclusive/universal design might be achieved with the active engagement of people with disabilities in design discussions.

ii. Expertise in Disability

Being the active voice controlling the disability discussions was connected to being the expert on their own struggle of sociologists with disabilities. During the disability movement, disability activists strongly rejected being under the control of experts with able bodies who, according to people with disabilities, have a limited understanding of disability. It was accepted to be supported by non-disabled people,

when necessary, with the condition of having a person experiencing disability as the leading role.

In a similar way, it was seen that architects were suggested to consult people experiencing disabilities to be able to design for all. The advocates of Universal Design claim that experiencing disability develops a particular understanding of the built environment that can help produce knowledge about accessible design. Moreover, it is known that the uniqueness of bodily experiences and their effect on design knowledge were emphasized in phenomenological studies.

With those ideas, people with disabilities were named as user/experts, and research studies were conducted to see the effect of consulting people with disabilities in detecting barriers and designing for all (Ostroff, 1997; Murrow, 2001; Ringaert, 2001). On the other hand, this secondary role of disabled people as consultants in architecture can be criticized for not offering equality for which the Social Model fought. This is why, the active participation of people with disabilities as architects in the profession should be supported to reach genuine disability rights.

iii. Epistemology of Ignorance

After examining Foucault's Chinese Encylopedia, it was seen that the unwanted, atypical identities were tried to be rejected by ignoring their identities. Similarly, according to the social constructive approach, people with disabilities were labeled as abnormal by disabling culture or houses to pursue the utopian society of non-disabled people and to protect the privileged position of non-disabled people. In addition, people with disabilities were removed from society and placed in institutions which eventually resulted in the needs of disabilities being ignored, and the hierarchical order of society was preserved.

Similarly, in the architectural profession, any imperfection in the user bodies was removed from the representations in the design books. By depicting male, able, healthy, heterosexual, and white bodies as the users, the identities of "other" or "misfits" were constructed. That situation resulted in the needs of people with

disabilities as the user being ignored. Some scholars believed that the reason for this ignorance was to protect the privileged position of non-disabled males in design and society.

Furthermore, the bodies constructed in society and architecture were criticized parallelly. The pioneers of the social model supported that the able-body is an unrealistic ideal. For those scholars, the able-body was only an abstract form that did not refer to the non-impaired body. Architectural representations were harshly manipulated to standardize the human body and resulted in unrealistic and non-existent abstractions. Similar to the discussions given in the agents of the change, having architects with disabilities in the profession did and would make the represented bodies more inclusive.

iv. The Unique Bodily Experience of Disability

After taking the place of the medical model, the social model has also been criticized by people with disabilities for ignoring the effect of the body on disability experience. According to those critiques, the social model used 'disability' and its definition as an umbrella term covering all disability experiences. Standardizing and grouping personal experiences of having an impaired body and trying to find solutions according to those standards were found to be reductionist by those people.

In the same vein, believing that adding measurements of wheelchairs and sensible surfaces into the design books was seen as reductionist by advocates of the philosophy of designing for all. The emotional and personal aspects of having impairments and the uniqueness of disability experience cannot be represented with standards. Instead, design theoreticians suggested that designers should gain insight and empathy to design for the unique experience of people with disabilities. That insight can be gained by being in direct contact with people with different abilities.

Moreover, it was seen that scholars studying spatial rights of people with disabilities are generally people who have a close relationship with disability. To conclude, designers experiencing disabilities might have adequate empathy to design for all.

v. The Marginalized Needs and Specialized Design

According to the human-rights-based understanding developed following the social model, a disabling practice in societies is marginalizing all the needs of people with disabilities by using the label 'special'. That practice reinforces the unfairly constructed social structure producing excuses to ignore the needs and preferences of people with disabilities, which results in people with disabilities being prevented from participating in social structure. The sociological discussions mentioned above indicated that invisibility and ignorance shape a vicious circle that solidifies the disabling practices of society.

Similarly, the specialized solutions added to design products to be used by different abilities are reconstructing understanding of designing for 'other', 'them', and 'the special' as if people with disabilities form a distinct group from the society. Moreover, those design solutions were found against the social model since they emphasize the user's bodily state.

Scholars suggested that architects design by taking reference from their own bodies, their colleagues' bodies, or bodies similar to them. Thus, the bodies different from those were associated with the terms other and special. Therefore, it can be concluded that increasing the number of differently able bodies in the architectural profession may prevent the discriminating labels that affect design understanding.

vi. Focusing on the system with the Feminist Approach

Lastly, with the understanding developed by the Social Model, disability researchers were asked to focus on the systems constructing disability instead of bodily states. Similarly, disability rights advocates who follow the feminist approach claimed that any non-disabled researcher should question the place of researchers with disabilities in their fields if they want to support disability rights. To illustrate, Barton (1996, p.4), who is a non-disabled scholar studying disability, suggested to non-impaired researchers to ask:

(a) “What responsibilities arise from the privileges I have as a result of my social position?”
(b) “How can I use my knowledge and skills to challenge forms of oppression disabled people experience?”
(c) “Do my writing and speaking reproduce a system of domination or challenge that system?

With that understanding, design researchers studying the spatial rights of people with disabilities may focus on the system of the profession of architecture. Accessibility of the profession with its faculty buildings, curricula, knowledge production methods, tools, and working conditions may be studied, and the effect of having students with disabilities in studios on the awareness of non-disabled students may be researched. That is to say; there are many questions that non-disabled architects can ask to empower people with disabilities in the system of architecture that constructs disabilities, instead of focusing on impairments and standards. For this study, the interrelated discussions in sociology and architecture were traced to indicate the necessity of participation of people with disabilities in architectural design and to evoke further questions.

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APPENDICES

A. Universal Design Paradigm

In order to promote creative design beyond accessibility standards and to make a broader range of designed products and environments be used by the widest pool of diverse abilities, a new strategy is defined by scholars, the discourse of Universal Design (Story, 1988; Sanford et al., 1988; Hamraie, 2016; 2017). The term 'Universal Design' was coined by Ron Mace, an architect and wheelchair user, and was defined as 'designing all products, buildings and exterior spaces to be usable by all people to the greatest extent possible' (Story, 1988; Mace, Hardie, & Place, 1996; Sanfold et al., 1998; Ostroff, 2001; 2011).

Mace also established the Center for Accessible Housing which is known as The Center for Universal Design today, at North Carolina University. With the idea that universal design can be difficult to achieve in practice, this center firstly defined a series of evaluations and then, with a group of working architects, product designers, engineers and environmental design researchers, the Principles of Universal Design were assembled to be applied to a wide range of design disciplines and user profiles (Story, Mueller, & Mace, 1998; Story, 1988).

The principles were listed as (Center of Universal Design, 1997):

> *Equitable Use:* The design that is useful and marketable to people with diverse abilities.
>
> *Flexibility in Use:* The design accomodates a wide range of individual preferences and abilities.
>
> *Simple and Intuitive Use:* Use of the design is easy to understand, regardless of the user's experience, knowledge, skills, or current concentration level.

Perceptible Information: the design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.

Tolerance for Error: The design minimizes hazards and the adverse consequences of accidental and unintended actions.

Low Physical Effort and Size: The design can be used efficiently and comfortably and with a minimum of fatigue.

Space for Approach and Use: Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.

While defining the principles it was aimed to increase the communicability of Universal Design (Steinfeld & Maisel, 2012) and to guide all the design process, the evaluation process of existing designs, the education of designers (Center of Universal Design, 1997). Moreover, it is believed that the principles can also be applied to the policies and action plans that are proposed to remove the barriers preventing people from participating in social life (Ginnerup, 2009).

B. Inclusive Design

Similarly to Universal Design, the Inclusive Design (ID) idea has been established by following the social model understanding that disability results from the disabling environments, products, and services that are designed without considering the abilities and needs of people with impairments and older people (Clarkson et al., 2003). Inclusive Design emerged in the mid-1990s in an atmosphere where there was a shift in attitude from treating disabled people and older people as separate parts of society to considering society as a whole (Clarkson & Coleman, 2015). When people with disabilities are differentiated from society, the designers tend to interpret those users as people requiring specialized Design (Coleman, n.d.). Inclusive Design, on

the other hand, supports designing for *the whole population* (Clarkson et al., 2003). Even though Inclusive Design and Universal Design are used as synonymous even by Coleman (Coleman, n.d.), there are some subtle differences (McGinley et al., 2022).

Roger Coleman (1994), the director of Helen Hamlyn Research Centre at the Royal College of Art, coined the term Inclusive Design by supporting that disability is a universal experience, and thus whole society should fight against disabling structures. Inclusive Design has been influential in the UK and offers a process-driven approach that necessitates "working with 'critical users' to stretch design briefs" (Coleman, n.d., p.22). While UD provides principles to make implementation easier, ID provides action lists to be followed by managers, designers, and educators. The action lists evolved around four main stages "audit > understand > improve > innovate" (Coleman, n.d., p.11-14). For designers, it was suggested first (1) to "understand the exclusion", (2) to "built appropriate knowledge" by engaging specialists, (3) to "acquire a better understanding of users/consumers" by working with organizations of disabled people or elderly or with consultants, (4) to collaborate with design schools to follow the improvements in ID, (5) to "capitalize on the potential for differentiation in the marketplace, and (6) to "develop tools and techniques" of ID and share them with design teams.

As seen, ID requires users to participate in the design and knowledge production processes. Inclusive Design stages' main idea is that if design can exclude a group of people by disabling them, it can also enable and include people (Clarkson et al., 2003) both after and during the design process.

C. Differently-Abled Architects in Turkey

It was also tried to reach diversely abled architects practicing in Turkey for this study.

For this purpose, firstly Chamber of Architects Ankara and İstanbul were asked if there were any records about architects with disabilities. On 05 and 26 April 2021, a

number of emails were sent to both branches, and a phone call was made with TMMOB staff; after those attempts, it was deduced that TMMOB did not have those records. However, it should be indicated that according to the meeting decisions, TMMOB (2021) has decided to keep the records of members with disabilities. Similarly, an email was sent to the General Directorate of Disabled and Elderly Services to ask if they could share any knowledge on architects with disabilities. They replied that Directorate kept no such record, but institutions related to higher education may have those records.

Then, the results of the Disabled Public Personnel Selection Exam (EKPSS) were examined. The numerical information shared by the Measurement, Selection, and Placement Center (ÖSYM, n.d.), shows that since 2014, more than fifty architects with disabilities have been employed to work for state agencies, primarily for municipalities and ministries. However, those numerical statistics do not give any knowledge other than the applicant's exam results, institution, and profession.

Lastly, by personal connections author has reached one architect working for the state, one newly graduated architect, and one architecture student, all of which have visible impairments. The details are not shared to protect their identities. Unfortunately, only one of those architects agreed to participate in any study or interview. Other architects respectfully refused to converse on their bodily states.

This process also showed some information that can be helpful for further studies. Firstly, there are a number of architects with psychological disabilities practicing in Turkey. Secondly, some architects, whom the author contacted, indicated that long working hours resulted in visual impairments and intense headaches. Moreover, diversely abled people practice in other design professions in Turkey.

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E. Map of the Inquiry into the Necessity of Participation of People with Disabilities in Architecture

For this thesis, different pieces of literature were examined, and how the interrelated discussions led to the idea that people with disabilities may contribute to the profession of architecture was visualized with a map.[4] By this method, the complex relations of the discussion were aimed to be simplified.

[4] The Qr code directs to the high-quality image of the map.

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