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## Visibility of dis/ability

Capturing shadows of ableism and disablism  
through a Photovoice-based approach

Metropolia University of Applied Sciences

Master of Health Care

Creativity and Arts in Social and Health fields

Master's Thesis

November 15, 2024

## Abstract

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Title: Visibility of dis/ability: Capturing shadows of ableism and disablism through a Photovoice-based approach  
Number of Pages: 68 pages + 3 appendices  
Date: 15 November 2024

Degree: Master of Health Care  
Degree Programme: Creativity and Arts in Social and Health fields  
Specialisation option: Occupational therapist  
Instructor: Dr Sanna Kivijärvi

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This master's thesis explores the experiences of ableism and disablism through an arts-based inquiry. The thesis aims to promote connections between people with different abilities and to form social capital. The research questions are: 1) What kinds of experiences of ableism and disablism can be recognised in and through a Photovoice-based approach?; 2) In what ways social capital between people with different abilities could be advanced in and through Photovoice-based workshops?

The conceptual framework for the study relies on critical disability studies that seek to challenge normative conceptions around body and mind and examine how society has constructed disability. It is a call for rethinking who is considered able or independent and examine how society marginalizes disabled individuals. This research was carried out as a qualitative study using an art-based research method, the Photovoice. The medium was part of a participatory research design in which participants documented their reality and collectively reflected on their experiences through pictures. The data analysis was done by applying qualitative content analysis.

The findings revealed a range of experiences on how ableism and disablism manifest in everyday life, including examples from urban structural inequalities to ableist and disablist ways of thinking and acting. Moreover, the participants reflected on ways for living all interdependently together while celebrating the diversity of all. Collective thinking and equal participation of all, were the most significant elements. Based on the findings, I suggest that arts-based inquiry has potentials for developing social capital between people with different abilities.

Keywords: ableism, critical disability studies, disablism, participation, Photovoice, qualitative research, social capital, social model of disability

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# 1 Introduction

For me, commuting by bus in Athens is not an option. I cannot get on the bus with my wheelchair. Commuting by metro is challenging too, as sometimes the elevators do not work, and I have to stop to a different station from the one that I want. Lastly, someone could say that moving on the road is dangerous, but for me sometimes is the only choice, as there are either no ramps, or they are destroyed. (Participant B.)

A driver accused of a hit-and-run accident involving a woman who is a user of a wheelchair in Athens (an accident happened in Athens 2024).

I am 27 years old and, in my life, so far, I have not met any disabled person (Participant A).

The first real-life example by research participant B, followed by a description of a car accident in Athens, and the last thought of research participant A, are three examples that indicate that people with disabilities continue to experience acts of discrimination and exclusion in and by society. The lack of accessibility, such as wide pavements and ramps, that force people sometimes to move on the road or not move at all around the city, affects and concerns everyone in a society as shown in the examples above. While few people recognise the role that society has in disabling people, the majority of people who are a basic element of society, are still not well-informed and educated. How can inclusion be discussed then, if the members that constitute society, are unaware of each other's needs? It is not the responsibility of people with disabilities to educate or inform others about their lives. Still, if they equally participate in society, all the members will eventually be familiar with them.

My professional experience as an occupational therapist, and my personal interaction with people who have a label as a result of a medical diagnosis, have

driven the writing of this paper. As Dan Goodley<sup>1</sup> (2014, p. 11) mentions, “If we know one thing it is that dis/ability is complex”. Studying about dis/ability needs people to have their minds and hearts open. There has been progress regarding the full participation of persons with disabilities as agents for change during the past decades. United Nations collaborating with Member States, Disabled People’s Organizations (DPOs), and other major stakeholders, support the rights and needs of disabled people. However, persons with disabilities are still facing many challenges in their everyday participation in society.

Dis/ability can be viewed through different perspectives and these perspectives define how society responds to the view of a disabled person. What is immediately apparent when someone starts studying about disability is the historical dominance of medicalised and individual approaches of disability that encouraged people to see disability as a “problem” that has to be fixed. This perspective has also been encouraged by a capitalist industrial society which prioritised profit maximization, and valued efficiency and productivity (Barnes & Mercer, 2005, p. 530). In this sense, individuals who may have a physical disability are seen as less productive, and in this way less valuable or “unfit” to the traditional labor market. This point of view is also connected to the theory of functionalism. As Donaldson (2002, p. 112) has mentioned, “functionalism views disability as a product of damaged body or mind that struggles to escape the pitfalls of essentialism and biological determinism”. This dichotomy and classification of who is lucky to be called “able or functional or normal”<sup>2</sup> and who is not, creates different forms of discrimination and racism against disabled people.

The oppressive practices of categorizing people and assuming that the normal way of living is the non-disabled, threatens to exclude, eradicate, and neutralise

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<sup>1</sup> Dan Goodley is a Professor of Disability Studies and Education at the University of Sheffield (The University of Sheffield, 2024).

<sup>2</sup> The quotation mark is used to imply that I am sceptical and critical of these words. I do not conform to rules that position who is normal/ able/ functional.

every individual with disability. The social hierarchy of the assumed normal, independent citizen tends to perpetuate inequalities and create barriers in the interaction of individuals within a society. Therefore, it is imperative to deconstruct and reform the cultural norms by decolonising dis/ability from this ableist medical industry. In this way, people will liberate themselves from ableist assumptions about dis/ability and explore forms of living based on solidarity, interdependence, and collective support. According to Žižek (2008, p. 123), it is essential “to celebrate collective solidarity, connection, responsibility for dependent others, duty to respect the customs of one’s community need to be celebrated – instead of Western Capitalist culture’s valuing of autonomy and liberal freedom”.

Douglas Baynton<sup>3</sup> (2013, p. 30) highlights the ubiquity of dis/ability. As he has mentioned “disability is everywhere in history, once you begin looking for it, but conspicuously absent in the histories we write”. Despite dis/ability’s ubiquity, the social realities of disabled people’s lives are continually ignored and considered as individual’s concerns (Mollow, 2017, p. 340). Even though everyone will experience some kind of dis/ability at some point in their lives, at the same time dis/ability sounds rather unfamiliar to many people. In a global context, the World Health Organization (2023) estimated that 16 percent of the world population, or 1.3 billion people, have disabilities. However, it is very common for people with disabilities to be segregated and hidden from the community.

The title of this master’s thesis “Visibility of dis/ability” is used not to imply that dis/abled people are not visible or to fight for their visibility. It is used as a point beyond visibility and inclusion. It is a call for engaging and exploring creative ways of living all together as human beings by letting false ideas about one another come to light and being open to redefining the experience of living with (or without) a dis/ability in contemporary society. The subtitle “Capturing the shadows of ableism and disablism through a Photovoice-based approach” has hidden meanings. Except for presenting the method of the Photovoice which was

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<sup>3</sup> Douglas Baynton is a Professor Emeritus at the University of Iowa in the department of History (The University of Iowa, 2024).

used in the research, this subtitle uses metaphorically the word shadow to reveal the way ableism and disablism exist in a society. The shadow is a dark area of which some people are aware, others are ignorant and few of them ignore it purposefully, just like ableism and disablism. The participants of this study are invited to document these shadows visually through photos. The purpose of this research study is to empower people with different abilities and encourage them to represent themselves. Moreover, this research aims to be a wake-up call for everyone to acknowledge the needs and experiences of dis/abled people. Hence, in this research project, people with different kinds of abilities interact with each other and share personal stories about everyday examples of inequalities created by the social context they live in. This master's thesis is a qualitative research study using an art-based research method, the Photovoice.

Before going deeper into this master thesis, I have to explain the way I am using some specific words concerning terminology. Words have power and I want to use them carefully. When I use the term impairment in my text, I refer to the state that the medicalized system has defined as a functional limitation in physical, cognitive, or sensory domains. Nevertheless, I do not imply that these individuals lack something. Regarding the terms disability and dis/ability, I use them both by critically choosing which one suits the meaning that I am trying to imply. The slash in "dis/ability" or its other variation (dis)ability, is used in disability studies to deconstruct any binary thinking around ability and disability and critique the ableist norms of ability and functionality (Campbell, 2009). Even though I recognize that dis/ability still focuses somehow on ability, I use this term to enlighten the theory and thinking behind my writing. Precisely, when I am using disability, I refer to the medical condition that a person may experience and the limitation of their participation in the community due to environmental and social barriers. Additionally, when I choose to put the slash in the word, I want to break any dichotomy between ability and disability. As an occupational therapist, I believe that every person is unique and can have diverse abilities and inabilities.

In Chapter 2, the conceptual framework is presented, which is based on (critical) disability studies, the concepts of ableism and disablism, Freirian (1970) social

oppression and the social capital theory. Following this, I describe the implementation of the research in Chapter 3, including the research task, question and methodological starting points. There is also a thorough description of the data construction, the analysis methods and the ethical issues taken into consideration throughout the research. The findings are discussed in Chapter 4 and final conclusions are drawn in the fifth Chapter.

## 2 Conceptual framework

This chapter examines how the topic of this research has been studied and analysed before and presents the conceptual framework that guided this research. The framework of this study includes concepts of dis/ability, ableism and disablism, (critical) dis/ability studies, Freirean social oppression (Freire, 1970), and the social capital theory (Putnam, 1993, 2000).

### 2.1 Definitions, (critical) thinking and concepts around dis/ability

Within disability studies many concepts have been developed to define and explore the concept of dis/ability. In what follows, three different models will be briefly described: the medical, the social and the affirmation. It is very important to discuss about these models because the way in which dis/ability has been viewed in them has great impact on how it is met by individuals, societies, and cultures.

Disability has been viewed and defined through centuries as a problematic situation and a challenge for an individual. The medical model describes disability as a deficit in the human body or mind, as a pathology (Wasserman & Ass, 2022). A biological deficit or abnormality that has to be fixed or changed by professionals (Forhan, 2009, p. 1383). The role of social and other environmental factors is ignored or underestimated as limitations faced by disabled people. A major problem created from this perspective is that medical professionals and scientists are acting mainly as an authority of society using diagnoses and labeling people to determine the treatment for each person. The issue with the professionals who act like an authority is that they do not take into account the feelings, thoughts, needs or values of the individuals whose lives are at the center. In this way, an imbalance of power is created between professionals and “clients” that hinders the collaborative, respectful and human-centered approach. Additionally, scholars reject this model because it puts the nondisabled as a normative ideal, obligating disabled individuals to make themselves more like the nondisabled (Gabriel, 2021).

Besides the medical-centered view of disability, the formulation of the social model of disability came to challenge the traditional understanding of disability as a medical issue. Before the 1970s, the main scholarly interest in disability was limited almost exclusively to more traditional, person-centered medical explanations as mentioned in the previous paragraph (Barnes, 2012, p. 17). Nevertheless, several key aspects especially between the 1970s and 1980s, drew attention away from the individual and focused on the environment. Precisely, the history of the creation of the social model was marked by the foundation of the Union of the Physically Impaired Against Segregation (UPIAS) in 1974. This organization was established by Hunt, Finkelstein and Davis<sup>4</sup> along with other like-minded dis/abled activists, all members of UPIAS, who highlighted the interconnected parts between dis/ability and social oppression. In other words, they explained the intricate relation of dis/ability with the social oppression similar to other minority groups (Barnes, 2012, p. 13). A significant work of them was the socio-political definition of disability that distinguished the biological aspect of disability, also known as impairment, and the social result of being disabled (Barnes, 2012, p. 14). In addition, the members of UPIAS published the Fundamental Principles of Disability. In that document they argued that “we are not disabled by our impairments, but by the disabling barriers we faced in society” (Oliver, 2013, p. 1024). The Fundamental Principles of Disability document was the idea behind the social model of disability (Oliver, 2013, p. 1024). All these examples are some of the various occurrences that led Mike Oliver, a disabled activist and lecturer, to formulate the social model of disability.

The social model sees disability resulting from the interaction between a person who is diagnosed with an impairment and a society with physical, communication and social barriers. Following this line of thought, society is the one that poses environmental, and cultural barriers that disable physically impaired people, and it is the one that needs a change. It is worth mentioning that a social model

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<sup>4</sup> Victor Finkelstein was a disability rights activist and writer. Paul Hunt was a disabled activist and writer. Ken Davis was a disabled activist.

perspective does not underestimate the right and person-centered interventions, like educational or medical. Nevertheless, it highlights their limitations regarding promoting the empowerment of dis/abled people (Barnes, 2012, p. 18).

The significance of the social model is easily understood, if someone takes into consideration that until very recently, in Western culture, disability has been viewed as a person's medical issue or a person's tragedy. Regardless of this model's importance, the social model of disability has several limitations. Oliver (2013, p. 1025) proposes two limitations. The first one is that impairment is not well captured in the social model and consequently it excludes important dimensions of disabled people's experiences and thoughts. The second implies that the model ignores the diversity of identities that a dis/abled person might experience at the same time resulting from their race, sex, age, social status and presents disabled people as a whole class. Nevertheless, the social model emphasized on the environment and played a key role in shifting away the focus from individuals.

All in all, the social model of disability redefined the problem of seeing disability as an individual issue, by differentiating disability from impairment and focusing on the oppression of a disabling society. However, the model does not consider that in an idealistic society that does not impose environmental barriers on people, dis/ability could be still viewed as a personal tragedy that differentiates people to normal and abnormal (Swain & French, 2000, p. 571). The affirmation model comes to expand this issue.

Swain and French (2000) introduced the affirmation model to give a different color, a more positive one to dis/ability identity. This model values the unique experience and understanding of dis/ability that comes directly from dis/abled people themselves (Swain & French, 2000, p. 569). The tragedy view of disability has been established by the social identity of non-disabled people who fear the vulnerability of their body and construct the identity of others. However, this creation of identity is not applied to themselves, but affects only the social identity of disabled people. This model is opposed to the personal tragedy view of

impairment and dis/ability, by supporting dis/ability identity. It is a criticism against the normality expectations of a society that promotes an ableist culture. Dis/ability identity is recognized and celebrated.

All in all, these models are not either one or another (Gabriel, 2021). Each has something to offer for understanding dis/ability better, recognizing dis/ability identity, and promoting inclusivity and diversity. It is not black or white, but a grey zone where people are invited to engage with all these models critically and take only what is valuable (Gabriel, 2021).

As mentioned before, dis/ability activists and scholars began to be more critical and politically active against sciences that researched disability and did a thorough critique over the medical model. All these actions, and in addition with the founding paradigm of this movement the social model, were the initiatives for the creation of a new academic discipline of study, disability studies. Shakespeare and Watson (2001, p. 547), suggest three principles that facilitated the creation of disability studies discipline. The first principle concerns the marginalization of disabled people as a group. The second idea regarded disability as a minority group and highlighted the need for mobilizing disabled people to act as a group for social change. The final one, was the creation of the social model of disability. Over the years, academics of disability studies have formed new ideas and concepts critically rethinking the basic principles of the field and forcing the rethinking of everything. As a result, Critical Disability Studies (CDS) emerged.

CDS came to challenge dominant ideas about dis/ability, deconstruct them and recognise the pattern why these ideologies regarding dis/ability have been constructed (Vehmas & Watson, 2014, p. 639). By rethinking about these ideas without denying them, the academics try to critically engage with them. The aim is not to focus only on dis/ability, but to understand the interrelations that this phenomenon is connected to and broaden the scope of dis/ability research. By following the path of CDS controversy can be a result, but high ethical responsibility is the final destination (Shildrick, 2012, p. 39). According to

Shildrick, critique is the key and the amazing opportunities and capabilities that creates, and she recognizes what Judith Butler has said:

What (critique is) really about is opening up the possibility of questioning what our assumptions are and somehow encouraging us to live in the anxiety of that questioning without closing it down too quickly. Of course, it's not for the sake of anxiety that one should do it...but because anxiety accompanies something like the witnessing of new possibilities. (Quoted in Salih & Butler, 2004, p. 331.)

CDS critiques the negative view of dis/ability by exposing cultural values around dis/ability that still focus on the medical condition. For example, one of the contributions of CDS was reshaping the societal views regarding the human body. A groundbreaking shift was made, differentiating dis/ability from the impaired body. According to Goodley's book, *Dis/entangling Critical Disability Studies*, "having an impaired body did not equate with disability. In contrast, disability was a problem of society" (Goodley, 2017, p. 84). Undoubtedly, the impaired body must be recognized and seen as a significant aspect of dis/ability. Impairments have their own realities on bodies, like pain, and must not be hidden. Besides that, other disability studies scholars have emphasized on the impaired body as a social body (Goodley, 2017, p. 85) that threatens to create an invisibility of the dis/abled individual. The way society designates some bodies as valuable or normal is questioned. They are seen as an interface where various identities intersect, like race, gender, age and others (Braidotti, 2003, p. 44). In this way, the non-normative body highlights the importance of diversity and emphasises the significance of inclusivity in how society values human bodies.

Following the CDS approach allows to acknowledge the complex association of ableism and disablism, leave behind the normal/abnormal binary and reimage "natural bodies". But first, there is a need to define ableism and disablism. According to the Universal Declaration of Human Rights, "all human beings are born free and equal in dignity and rights". However, at the same time some people are categorised as different and have less opportunities for participation as they are devalued. One category of difference between people, like gender, race, class, or age, is ability (Collins, 2015, p. 14) and people tend to be categorized

according to their abilities (Goodley, 2014). Contemporary society has some preconditions, like being able of living independent, walking, managing everyday struggles alone. If someone does not match with these preconditions is seen as different (Campbell, 2009). This is due to ableism. Campbell (2001, p. 44) defines ableism as:

a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical, and therefore essential and fully human. Disability then is cast as a diminished state of being human.

This social norm indicates who is acknowledged as an able and functional human in society. Yet these social norm ideas are not always obliged. Campbell (2009) refers to the phenomenon of internalized ableism to talk about the way disabled people sometimes adopt and apply some stereotypical views imposed on them by society. More specifically, she defines the concept of internalized ableism as “how disabled people learn to view themselves as lesser, separating themselves ontically from ‘the normal’ and from ‘others’ as being different, special and unsuitable” (Campbell, 2009).

Ableism makes disability invisible, replaceable, and less than human (Dolmage, 2017, p. 7). The thought that ableism concerns only the dis/abled people is an illusion. On the contrary, ableism is a matter of everyone through its normality spectrum, as it sets boundaries to people on how to act, talk or act in order to reach the “ideal norm” (Dolmage, 2017). Nevertheless, meeting all necessary preconditions is demanding and unrealistic. The ableist body or self is a normative construct that does not exist as it is an invulnerable idea of being (Shildrick, 2002, p. 51). It guides us regarding how people are supposed to want to be but can never become and denies the dis/abled body or mind. Besides that, neoliberal ableism also critiques the way contemporary society values ideas of self-sufficiency, individualism and material wealth (Goodley, 2014). It associates happiness with self-reliance and productivity. In this way, all members of modern society are at risk of not feeling complete or sufficient (Goodley, 2018, p. 4). If someone does not meet this ableist criterion of the self-sufficient, autonomous,

independent, and happy citizen, is rendered disabled. Therefore, everyone faces the risk of questioning their ability during their life. But who is considered “normal” and therefore able?

Davis<sup>5</sup> has analysed in his work (2002) the temporary aspect of “normalcy”. For Davis (2002, p. 31) “impairment is the rule, and normalcy is the fantasy”. This concept recognises that “normal” body cannot be fixed and defined due to its diversity. All bodies are different, change through lifetime, and sometimes hurt by unpredictable accidents. Therefore, the ideal normal body cannot exist. Davis invites scholars to shift their focus from categorising dis/abilities to developing interventions that enhance abilities. Consequently, someone will have the right to be ill or impaired without suffering discrimination or oppression.

Ableism has significant results on how people see each other, themselves and act according to these views. These ableist worldviews then preserve and promote disablism (Goodley et al., 2012, p. 5). For Campbell (2009, pp. 3–4), disablism is “a set of conscious or unconscious assumptions and practices that foster the different or unequal treatment of people because of their actual or presumed disabilities”. Another definition of disablism by Carol Thomas (2007) is “a form of social oppression involving the social imposition of restrictions of activity of people with impairments and the socially engendered undermining of their psycho-emotional well-being”. Disablism is therefore any practice or idea that devalues people due to their disability and excludes them from several settings in everyday life.

Ableism and disablism feed off each other as disability cannot exist without ability (Goodley, 2018, p. 7). For disablism to be persist, the underlying concept of ableism is required to be present (Goodley, 2018, p. 5). Ableism can be seen as the system that fuels disablism. The difference between them is the recipient of these mechanisms. Everyone during their lifetime will not be considered as

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<sup>5</sup> Lennard J. Davis is an American specialist in disability studies.

“normal” or as its synonym “independent”. However, only disabled people will be discriminated against and oppressed by disablist actions (Baglieri & Lalvani, 2019; Campbell, 2008). Disablism often manifests in different settings of everyday life through the segregation and exclusion of disabled. For example, an ableist assumption could be that being disabled and needing help for doing some everyday occupations, like taking the metro, is embarrassing. A disablist practice would be to internalise that ableist assumption and not take the metro in the fear of being stigmatized and considered as less capable.

Examples of these oppressive ways of thinking and practices of ableism and disablism can be noticed in different settings of everyday life. For instance, studies have shown that dis/abled people still face workplace discrimination due to ableism and its disabling effects (Berghs et al., 2021; Dick-Mosher, 2015; Jammaers & Zanoni, 2021; Jammaers et al., 2021; Vedeler, 2014). While the World Health Organization (WHO, 2011) shows that employment rates vary across countries, the rates of unemployment of disabled people are commonly high everywhere (Heymann et al., 2014, p. 4). An ableist workplace has very specific criteria for who is capable of working. Individuals who lack specific preferred abilities or are perceived as lacking them are marginalized. These capabilities are synonyms of productivity.

Moreover, the highest rates of imported incidents of workplace harassment and unnecessary discrimination and exclusion are by employees with dis/abilities (Bam & Ronnie, 2020; Jones et al, 2018; Nxumalo, 2020). With regard to physical accessibility, the lack of ramps, walking rails or lifts with braille signs, is an example of exclusion and discrimination. Additionally, racism can be seen in the workplace culture and microaggressions in everyday interactions between workers. Ignorance, fear, and stereotyping are still widespread. In the hiring process, discrimination can be witnessed as unfair practices of selection or even superficial efforts to include a minority to a workplace without genuinely promoting equity and diversity. Disabilities that are not visible sometimes are not taken seriously and disabled people can be treated differently from the other workers.

This exclusion of dis/abled people from the labor market has been the main reason for their marginalization (Barnes & Mercer, 2005, p. 541).

One context in which ableism takes place is in policies and beliefs in the physical environment. By existing in a built environment, people may interact with the physical space, but at the same time they also interact with the people that have built it. Therefore, they come across with all the assumptions and attitudes of people whose opinions shaped these structures and facilities to be accessible or not (Reber et al., 2022, p. 17). The physical structure of space articulates the unspoken truth of who is welcome, wanted, included or excluded (Sibley, 1995, p. 224). Therefore, an inaccessible environment marginalizes dis/abled people and isolates them. This isolation makes their presence in society invisible and later their needs are purposefully ignored (Reber et al., 2022, p. 18). It is a cyclical process in which ableism is present.

## 2.2 From social oppression to the formation of social capital

Paulo Freire is a key person when working or studying with people belonging to a minority group. His philosophy-based work "Pedagogy of the Oppressed" (1970) was revolutionary and has been applied to different social justice areas. According to Freire's (1970, p. 55) theory, oppression is defined as:

Any situation in which "A" objectively exploits "B" or hinders his and her pursuit of self-affirmation as a responsible person is one of oppression. Such situation in itself constitutes violence, even when sweetened by false generosity, because it interferes with the individual's ontological and historical vocation to be more fully human.

This dynamic perpetuates inequality and restricts the freedom and agency of the oppressed group. It hinders people's freedom to exist in their world. It is about the domination of power over a powerless group of people whose voice has been muted or avoided. This exclusion has different forms and varies with economic

and social conditions (Oliver, 2009). Forms of this exclusion range from violation of people's human rights, not respecting their dignity and needs and even institutionalisation. For example, a person with disability may have less flexible access to public transportation and fewer opportunities for higher education or finding possible employment. Regarding Freire (1970, p. 56), "it is only the oppressed who by freeing themselves, can free their oppressors". They are the ones who can liberate themselves, take their agency back, and at the same time free their oppressors too. The key to this liberation is the dialogue. Human existence cannot be silent (Freire, 1970, p. 88). Human beings need to name their world, their experiences, and their thoughts. "To exist humanly, is to name the world, to change it", as he has mentioned (Freire, 1970, p. 88). That is why to be seen is dialogue. People teach each other (Freire, 1970, p. 80) and everyone has the right to speak their world and participate in this dialogue that is an existential necessity (Freire, 1970, p. 88).

People with an impairment have also to face the imposed results of disability, which are unnecessary marginalization and exclusion from full participation in society. Therefore, disabled people are an oppressed group in society (Charlton, 1998, p. 10). Disability oppression is a complex phenomenon and can be witnessed in various domains in a society. According to Charlton (2006), three forms of oppression can be named. Precisely, poverty and the lack of power that results from it, are one of the main aspects of disability oppression which make them dependent on others. In addition, cultures and beliefs can potentially contribute to social oppression. The social norms that highlight the ideas of the normal and abnormal body, separate people regarding their abilities and classify them into systems. The third form of disability oppression is the internalisation of these norms by disabled (Charlton, 2006, p. 220). This creates an alienation and false consciousness that marginalizes individuals because it prevents disabled people from knowing their true capabilities and needs. Some examples of oppression experienced by disabled people can be regarding disabled people necessarily in need of care and attention or reinforcing unduly negative images and perceptions of them (Thompson, 2006, p. 135).

Consequently, there is a need to find ways of building social connections between people with different abilities and providing opportunities for full participation in the society. The significance of social connections to people's lives has been well captured in Putnam's theory of social capital (2000). Social capital theory argues that social networks offer people numerous benefits in many ways. People become stronger in a community and thrive as they have more possibilities for achieving goals that improve their lives. These kinds of networks can be families, schools, organizations and even whole societies. Regarding theory, social capital can be developed in three possible types: bonding, bridging and linking (Putnam, 1993, 2000). Bonding social capital refers to the strong ties among people who share similar cultural values, goals and experiences, and provides support and a sense of belonging (Putnam, 2000). Bridging social capital are networks that connect people from different circles and provide them with new perspectives. Last, linking social capital emphasises on connections between people from different levels of power (Putnam, 2000).

Since social capital is based on strong collective action, then it is obvious that this theory does not have a place for exclusion (Putnam, 1993). On the contrary, some of its important components are trust, tolerance of diversity, and participation. It has been argued that several issues are preventing disabled people from experiencing social capital (Chenoweth & Stehlik, 2004, p. 66). One of these issues is their social isolation from the wider community (Chenoweth & Stehlik, 2004, p. 66). Individuals are dependent on social relations and networks of support whether they are disabled or not. Therefore, this research acknowledges that dis/ability is not an individualistic trait but concerns everyone in a community sooner or later. Consequently, creating support systems and including all the members of a community is necessary.

This research is not about helping marginalised people join "our life" but enabling new ways of living together. Living together means that all people have equal rights and opportunities. In this thesis, I am using the definition of dis/ability by the social model perspective that transformed dis/ability from an individual issue to a human rights concern (Barnes, 2012, p. 23). People having some kind of

medical condition in their body or mind, do not have to undergo the oppressive circumstances of an ableist society. Dis/ability is something caused when an environment full of barriers makes some people excluded.

### **3 Implementation of the research**

In the third chapter I am focusing on the research task and question, followed by methodological starting points. Then I am presenting the methods and processes of data construction and analysis. Finally, I am ending the chapter by diving into the ethical considerations of this research.

#### **3.1 Research task and question**

This master's thesis explores the experiences of ableism and disablism through an arts-based inquiry. The thesis aims to promote connections between people with different abilities and to form social capital. To meet this aim, a space where the experiences of the participants are heard and recognized was created. The study also aims to enhance the understanding concerning the experiences of dis/abled, redefine the given meaning to dis/ability and the way society creates dis/abilities. Hence, people with different kinds of abilities participate and share experiences and stories about everyday examples of inequalities created by the social context they live in. The participants will have the chance to recognise examples of ableism or disablism in their everyday context of living, capture them, and then lead the discussion based on what they feel is more important for them. Moreover, photos have a strong emotional impact and can be a documentation of the present.

The research questions of the study are:

What kinds of experiences of ableism and disablism can be recognised in and through a Photovoice-based approach?

In what ways social capital between people with different abilities could be advanced in and through Photovoice-based workshops?

### 3.2 Methodological starting points

This master's thesis is a qualitative research study applying arts-based research methodology. According to Leavy (2017, p. 124), "Qualitative research values depth of meaning and people's subjective experiences and their meaning-making process". It has also been described by Denzin and Lincoln (2018, p. 43), as an attempt to "study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them". The production of non-numerical data is a result of discussions, observations, notes, life histories and visual methods. Through this process, the researcher can delve deep into the context and understand better the human behavior and a social phenomenon. The place of the research is the natural settings of people to understand how their experiences are shaped by the context of their lives, physical, economic, cultural, or social. These approaches are most often used in explanatory or descriptive research (Leavy, 2017, p. 124). Qualitative research is particularly beneficial when someone wants to understand in depth a social phenomenon from the individuals and small groups of people whose lives are at the center of this (Leavy, 2017, p. 159). That is why this type of research is very common among academic researchers in social science fields (Breeze, 2023, p. 139) because a researcher can delve into a topic properly.

The philosophy that influenced qualitative research was the philosophy of positivism (Leavy, 2022, p. 104). The theory of positivism underlines that professionals can observe, measure and analyse the reality of their world that exists regardless of the research. The aim is to interpret the laws that govern the social world through hypotheses and build evidence to support a hypothesis or reject it. "There are two major concepts within which qualitative researchers typically work: interpretive/constructivist and critical" (Leavy, 2017, p. 129). According to Leavy (2017), the interpretive/constructivist paradigm focuses on understanding the subjective meanings that people connect with their experiences and social interactions. Therefore, it focuses on the interaction between people and their interpretations. This paradigm includes a phenomenological approach where the researchers ask how people encounter

the topic under investigation without aiming to affect their considerations. Besides that, the critical paradigm goes beyond only understanding, by actively questioning power relations and inequalities. Whereas this paradigm is connected to social justice. While my study does not necessarily align with the critical paradigm, as it does not focus on societal power dynamics, these issues inevitably arise when exploring the experiences of dis/abled people who belong to a minority group. Consequently, my research follows the interpretive paradigm but still has some elements of the critical.

Arts-Based Research (ABR) brings the principles of creative art to social projects. Creative and arts-related mediums in research allow researchers and participants to seize the capabilities of arts as a way of knowing, raising awareness regarding various issues and enabling interpersonal meaningful connections (Leavy, 2017, p. 191; Leavy, 2020, p. 15). Consequently, human cognition and behavior are better understood. The purposes and possibilities of ABR are various, but I will focus on the specific ones that encouraged me follow these approaches. First of all, ABR has been employed as a medium for deconstructing, questioning stereotypical ideologies and raising the voice of those who are often marginalized. Driven by the social justice movement of the 1960s and 1970s, many researchers seek out the voice of the people who have been marginalised and arts-based projects are particularly effective for including them into research. To give an example, many times ABR has been used for conducting research with people who have been marginalised because of dis/ability (Kalenderidis, 2020; Kalenjuk et al., 2024; Payne et al., 2016; Power et al., 2022). Furthermore, arts-based practices offer the freedom to capture different meanings and truths. Thus, multiple interpretations come to light rather than enforcing definitive claims (Leavy, 2020, p. 27). For example, if two people observe a piece of art, this piece will awaken different feelings, thoughts, or memories in each of them as there is no one approved way in the process of meaning-making in arts. In this way, the researchers are not seen as “the experts” and the meaning-making is democratised. Finally, arts-based methods can be an opportunity for nurturing dialogue which is a key component for creating meaning and understanding

(Leavy, 2020, p. 27). The method by which individuals are encouraged to join a dialogue through arts is very immersive and can elicit strong emotional reactions.

### 3.3 Construction of data

The construction of the data for this research was manifested through using semi-structured interview questions for facilitating dialogue and an arts-based participatory visual method. Discussions were held out and at the same time, an arts-based participatory method was used to offer to the participants a non-verbal way to tell their truth. All the online discussions were recorded by Zoom which offers the possibility for recording and automatically saving the audio files to the computer. Then, I transferred the audio files to an external hard drive and erased the files from the computer. The external hard drive was safe at a private place that only I had access to. The arts-based participatory visual method chosen to construct data is Photovoice. Photovoice is a participatory action research method shaped by the Feminist theory and Paulo's Freire critical pedagogy (Wang & Burris, 1997, pp. 370–371). Over the years, it has been used in a variety of research projects different from the one that Wang and Burris first introduced it in the early 1990s. Photovoice was initially developed for raising the voice of women, offering them a medium for telling their truth and empowering them (Wang & Burris, 1994, p. 179). Since then, it has been used in numerous and different settings, such as for exploring the experiences of students with a mental illness on a college campus (Skoy & Werremeyer, 2019, p. 1), for understanding the perspectives regarding sexuality from the viewpoint of young physically disabled women (Payne et al., 2016), for empowering students to advocate for change to the smoking policy in campus (Seitz et al., 2012, p. 537). Wang and Burris state that "Photovoice is a process by which people can identify, represent, and enhance, their community through a specific photographic technique" (1997, p. 369). This technique is a medium for people to tell their truth, enable them to critically reflect on their life circumstances and potentially trigger social change as it is based on Freire's thinking (Freire, 1970) of problem-posing education that people have the agency and through dialogue they can identify oppressive situations. Therefore, in Photovoice participants take agency by getting a camera,

capturing their reality, and later reflecting either alone or all together about their life circumstances.

Recruitment of the participants was completed through purposeful sampling (Leavy, 2017, p. 148). This way of recruiting people is especially suitable for this research because it allows the researcher to find the most suitable participants for the study and not everyone necessarily is interested in taking part in arts-related activities. The participants were found from the researcher's own connections and were invited through an informational email. Moreover, the snowball strategy (Patton, 2015) was used. The only criteria for participating in this research were that the participants had to be legally adults, and if they have a dis/ability, it must be physical dis/ability. The research will draw links with the social barriers that are relevant to people living with their physical condition. A limitation resulting from this decision is that people with other kinds of dis/abilities are not included. Nevertheless, this decision was right due to the time restriction and the aim of the thesis. Precisely, the time frame of the thesis was limited for being able to include more people with different dis/abilities as they would need different inclusive tools to enable their participation. For example, if some people could not use a camera with their hands, I should have supplied them with alternative equipment, or if a person could not communicate in a verbal way, I should have included different mediums of interaction and communication. Additionally, the aim of the thesis is not to focus on the type of dis/ability, but on the social barriers.

Photovoice then is a participatory method for conducting research in which participants document their realities through cameras, reflect on them, and ignite a dialogue regarding their life circumstances. The ideal number of participants for a photovoice project is between three and ten people (Hamilton Community Foundation, 2007, p. 6). Consequently, the study community in the first meeting consisted of five participants, and in the second meeting were three, as two participants withdrew. There were two meetings that both lasted for two hours, and they were held online. Online contact, that is a contact that occurs in online environments among individuals belonging to different groups, is a form of

indirect contact and it was chosen, as indirect contact can be especially relevant to produce generalised reduction in prejudice and promote positive intergroup relations (White et al., 2021, p. 144). In addition, online meetings are inclusive as they break down the barriers of physical accessibility<sup>6</sup>. For the online meetings, the platform that was used was the web conference tool Zoom. In this way, the participants had the opportunity to use cameras and interact more with each other. In addition, the Jamboard platform, which is a digital whiteboard app, was used to let the participants collaborate in real time and share their thoughts.

The participants were all from my birth country Greece. Therefore, I conducted the research in their mother tongue, Greek, for many reasons. Firstly, when participants communicate in their mother tongue, they can express themselves clearly and more naturally. I wanted people to feel comfortable, safe, and consequently more engaged. Second, language is deeply tied to culture. I value the cultural identity of the participants and by allowing them to express themselves in their language, I wanted to have a deeper insight of their reality and their worldview. Finally, attempting to have a discussion around sensitive topics, like race or dis/ability or oppression, can be uncomfortable and easily misunderstood. By ensuring that all people spoke fluently the language in which the research was completed, I made sure that all people understood the purpose of the study, could engage in conversations equally, and tell their truth clearly.

*First session. Duration 2h.*

For the initial session planning I made sure that I combined multiple communication methods to make the event more accessible (Henry, 2022). I included verbal information, a Power Point presentation with pictures and less amount of text, and a text. The first online meeting started by setting up the safer space guidelines for making sure that there is a supportive environment where everyone can feel comfortable to express themselves. It was time then to promote

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<sup>6</sup> A master's thesis elaborated on ways for boosting inclusivity of hybrid events is by Maj Ilola (2023).

the interaction between the participants and getting to know each other. Creative group activities allow individuals to engage with others, influencing their interaction and at the same time being open to be influenced by it (Huhtinen-Hildén & Isola, 2019, p. 10). A poetry game was facilitated, and all participants shared some words about themselves. Then, by combining these words, their own poem was created. Next, I shared some informational material regarding the framework of the study and the technique of Photovoice. Having this theoretical input the participants were asked to reflect on examples they have encountered ableism or disablism in their everyday life and other examples of social barriers that create disability. Afterwards, since dis/ability art is known as a powerful way to promote a positive dis/ability identity (Solvang, 2012, p. 179), I shared a poem written by Neil Marcus<sup>7</sup> called “Disabled Country” to introduce the theme of disability culture. This poem has been videotaped too on YouTube, so the participants could choose to either watch it or read it. Finally, after reflecting on the poem and sharing thoughts and emotions, we chose all together the subject of our Photovoice technique and we set the date of our next meeting two weeks later.

For the next two weeks, participants were asked to use a smartphone camera to capture photos which for them represented the theme of “Dis/ability and society”. They could take as many as they felt necessary up to 10 exposures. They had two weeks to take the pictures, reflect on them privately, and send them through email to the researcher. To facilitate their personal reflection a journal manual was provided to record their thoughts about each photo using the SHOWED technique. The SHOWED technique given in Table 1 is used in Photovoice research before (Dowhaniuk et al., 2021; Skoy & Werremeyer, 2019; Werremeyer et al., 2020). It is a set of five questions that encourages the photographer to reflect and elaborate on the pictures. All photographs were developed in duplicate to allow participants and researcher to have a copy.

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<sup>7</sup> Neil Marcus was an actor with many other interests. As he mentions, “disability is not a brave struggle or courage in the face of adversity, disability is an art” (Kuppers & Marcus, 2009).

The <b>SHOWED</b> technique	
S	What is <b>S</b> hown here?
H	What is really <b>H</b> appening here?
O	How is this related to <b>O</b> ur (your) lives?
W	<b>W</b> hy are things this way?
E	How this image <b>E</b> ducate people?
D	What should be <b>D</b> one about this?

Table 1. The SHOWED technique questionnaire

Descriptive interpretation: Table 1 shows 6 rows. Each of them has a question that every participant must reflect on their pictures.

*Second session. Duration 2h*

In the second and final meeting, there were three participants, and the meeting started with sharing some general news and feelings about the day. Then I did a quick summary of what we did and discussed last time, and I reminded everyone of the safer space guidelines. As the previous time I noticed that some participants were hesitant when talking about the politically correct terminology for disability, I did a presentation about the language guidelines, after making sure that it was something that they would like to have. Following this, it was time for the participants again to take a step forward and present their pictures. More specifically, they presented their pictures and shared their thoughts, feelings and ideas about them while connecting the pictures to the theme of the photography. Everyone was free to make questions, critical comments and express feelings. The participants did express their assumptions or questions concerning various subjects regarding living with a disability and the disabled participant was open to answering them. After the presentation of the pictures, the participants expressed their intention to find a way to keep in touch and meet in person as

they felt a connection. Lastly, I gave them four questions that the participants chose to answer later by email. The questions were:

- What do you think after this research about disability and society?
- What forms of everyday of ableism / disablism can you think of?
- What is needed to live all together interdependently? How arts/ creative related activities can contribute to that?
- Was this research helpful for promoting connections between people with different abilities? If not, what could be done differently?

### 3.3.1 I as a researcher

In this subchapter, I present my role in the research meetings and my role as a researcher. As a new researcher with no previous experience, I had my eyes, ears, heart, and brain open for critical feedback and advice. I was aware of lacking the practical experience of a researcher, but my passion for this topic and my genuine interest in researching ethically, made me truly dive into this process. I read about the skills needed for researchers and arts-based researchers in a variety of methodology and methods-related books (Abma et al., 2019; Leavy, 2020; Nind & Vinha, 2014). When reading about the beginning art-based researchers, I wanted to keep in mind that research is a learning process and keep in my heart the quote “Worry less about being ‘good’ and focus on being engaged” (Leavy, 2020, p. 33). That is what I did. I was fully present in the process trying to listen to the participants and understand their meanings. In the first meeting, I wanted to give more freedom to the participants. I posed open-ended questions, and I did not navigate the discussion. In this way, I wanted to know their own experiences, knowledge and thoughts about disability. I wanted to discover the variety of the topics that will be discussed and how aware the participants are about the subject. However, since I observed that the discussion was too broad and around many different topics concerning disability, in the second meeting I had more structure, and I encouraged all the participants to answer specific questions about “Dis/ability and society”. Finally, I always

reminded myself to enjoy the creative process, as Einstein<sup>8</sup> said “Creativity is intelligence having fun”.

Personally, the spark for studying and researching topics related to dis/ability stems from my personal and professional background. After a short time working as an occupational therapist, I realised that occupational therapy interventions focus mainly on the individual, trying to fit them into some “normal” standards set by a group of doctors. Even though I recognise the importance of individual interventions in empowering people to be more autonomous and possibly go through potential body pain, they are not enough. In an inclusive society, the society is the one that ensures that all people belonging to it have the same opportunities and resources for participation. People belonging to it are not responsible for “changing” to fit the society’s criteria; therefore, I wanted to turn my attention from the individual to the society. I wanted to see the whole forest and not only the trees. This was the triggering point for conducting this research. I wanted to form social capital between people with different abilities and raise people’s understanding of disability. In the end, people are all different and that is their power. However, I recognise the complexity of inclusion. Creating an environment of equal opportunities and choices for participation is complicated, as everyone is unique. Nevertheless, I would like to dive into this journey and possibly create knowledge about it. I do not consider myself neither normal nor able-bodied. I am just a human being with some abilities inviting other people to find ways of living interdependently altogether.

### 3.4 Data analysis

Then it was time to analyse my data. The audio files from the online meetings and the consent forms were organised into files and kept on an external hard drive. The pictures with the SHOWED sheets were also filed and kept on the same external hard drive. All the material was prepared for analysis after

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<sup>8</sup> Albert Einstein was a German-born physicist and is generally considered the most influential physicist of the 20<sup>th</sup> century (Brittanica, 2024).

transcribing it in World for easier processing. The recorded group discussions from the two meetings were transcribed on a total of 60 pages, the pictures taken were 10, and three of the participants answered four written questions after the research meetings. Personal identification data were removed, and participants' names were replaced by their corresponding numerical representation in the document. After pseudonymisation, all this transcribed material was printed and kept in a place in my home to which only I have access.

The qualitative content analysis was the most suitable data analysis method for the research. Firstly, I wanted to get a sense of the data and get back to their heart after their organisation and pseudoanonymisation. As Leavy points out, it is easy to lose sight of the big picture while organising the data, the researchers must immerse themselves back in it (Leavy, 2017, p. 150). Therefore, I went over the material repeatedly and when I was familiar with it, I started to take some first notes, underline important sections, and write down in the margins some first thoughts. Specifically, once the text was organised and pseudonymised, I read it many times and when I almost knew it by heart, I highlighted and selected phrases from the discussion related to the research question. While analysing their words, I used also their pictures and the SHOWED sheets to facilitate the process. I was trying to interpret the message, and the feelings conveyed through their pictures and identified a connection with their sayings. Photographs gave me a holistic understanding of the data, as except of their words, I had a visual documentation of their reality.

“Coding is the process of assigning a word or phrase to segments of data” (Leavy, 2017, p. 151). I did it by hand and the approach that I followed was the vivo coding which allowed me to use the participants' language. Coding allowed me to reduce my data too and classify them. On one hand, the point of the data reduction is to remove content that is irrelevant to the research and on the other hand, the goal of data classifying is to categorise original expressions that describe the same concept. The categories are named with a concept that describes the content. Categorising needs to look for similarities, patterns and relationships between the codes. I wanted to find and generate the themes behind the codes to interpret

their relationship afterward. As I am a visual thinker, every expression that described the same concept was written in one colour of Post-it paper and every concept had its colour. The themes that came firstly to the surface are:

1. transforming discriminatory attitudes and assumptions (Colour red)
2. making the invisible visible through participation (Colour yellow)
3. the collective 'us' (Colour pink).

The time to find out what all these themes mean and interpret them has come. During interpretation, the data is getting a meaning based on links the researcher finds between various concepts and categories (Leavy, 2020, p. 152). Throughout this process, I had always by my side the theoretical approaches behind the research and the conceptual framework that guided my perspectives on the subject. In other words, I organised the three themes of the data and tried to understand their meanings and then I connected them to existing theories of the framework that guided this research, the most central of which is ableism and disablism. The conceptual framework served as a value base throughout the research planning and implementation. It was a guide for me to know for example how to interact with the participants or what lenses to have while interpreting the results. While interpreting the visual data (the photos), I focused on understanding their symbolism and the social reality that is captured. Their interpretation aimed to clarify what is happening and why and then connect that to theory.

Lastly, while I was interpreting my data, I always had in mind the research task and question. I had to change my research question to better align with the evolving direction of my study. The initial one was too broad including the general understanding of people concerning the experiences of persons with dis/abilities. However, the discussion of the participants and their pictures focused on examples of ableism and disablism in their everyday lives and what should happen to change this situation. After further exploration of the literature and critical feedback from my peer students and my advisor, I realised that changing my research question would allow me to address a more focused issue and

generate meaningful insights. This adjustment also ensures that my research conclusions reflect the real key areas of participants' inquiry and interest that are significant to them.

### 3.5 Research ethics

The ethical research principles established by the Finnish Advisory Board on Research Integrity (TENK) in 2023 were carefully followed and respected throughout the whole research. These ethical guidelines foster responsible integrity and ensure an ethical creation and distribution of knowledge (TENK, 2023).

All participants were adults, and their participation was voluntary. They were given two different consent forms to sign. Firstly, the information sheet mentioned clearly the aim of the research, the rights of the participants, and their responsibilities (Appendix 1). Secondly, a consent form was signed, as an indication that the participants read, understood, and agreed with the information sheet (Appendix 2). Moreover, it included a signature obtained by the photographer, from the subjects whose pictures were taken.

I as a researcher aimed at creating a safe place for all the participants. A place with respect to the participants, and their culture, where they can freely express themselves and their honest thoughts and emotions. A place where all the voices are heard, and values like empathy, respect, and equality are blooming. This is the reason why, I set a guideline of a "safer place" that guaranteed a non-judgmental environment, and the participants could add their preconditions if needed.

Regarding the ethical perspectives of the Photovoice method Wang and Redwood-Jones (2001) in their work, although it is dated, cover eloquently issues of privacy, safety, autonomy recruitment and representation. Following them, in the first meeting a discussion concerning the use of cameras, power and ethics, was facilitated (Wang & Redwood-Jones, 2001, p. 569). Moreover, they highlight a set of ethical concerns that I took in consideration. Specifically, Allen (2012)

organizes very effectively the ethical concerns that Wang and Redwood-Jones (2001) call attention to. Specifically, these ethical concerns are:

(1) individuals have a right to privacy in both private and public spaces, and though it may be legal to photograph someone in public, it may not be necessarily ethical; (2) participants need to understand and identify contexts in which consent is needed; (3) the safety of participants must be considered as photographs produced can cause embarrassment among those photographed and may cause retaliation towards the participant; (4) participants should own the prints and negatives they produce to prevent commercial exploitation and appropriation; and (5) researchers may intentionally or unintentionally influence the kind of images produced through the directions they provide to participants. (Allan, 2012, p. 9.)

Considering all these ethical concerns, I attempted to provide as much as more detailed and clear information to the participants regarding their photos. I saved all photos with an extra digital copy on my personal protected computer until data analysis was completed and then I deleted them. I wanted to include all the visual data into my research report. Therefore, in the consent form, I included a request regarding the use of the photos that reflect the themes discussed with the participants. Although, it was necessary that the pictures would not include people but events and objects of people that would be easily anonymised without altering the photographic meaning. The number of the photos taken is ten and they are all included in the paper.

Nevertheless, since Wang and Redwood-Jones' (2001) article on *Photovoice Ethics: Perspectives from Flint Photovoice*, the world has experienced various changes, such as the digital revolution and other emergent ethics issues were taken into consideration. More specifically, the issues are the inedible images, the representation, and the vicarious trauma (Creighton et al., 2018). To avoid them, I included in the consent the potential risk that shared pictures may be copied and/or used outside the original study agreement (Creighton et al., 2018). About the issue of representation, actions will be taken into consideration in case of a potential exhibition of the pictures. Lastly, I considered the risk that interviews can possibly cause participant distress. That is why, I sensitively discussed with all the participants respecting the timeline, their well-being and energy levels.

## 4 Findings

This chapter presents the findings answering the research questions: What kinds of experiences of ableism and disablism can be recognised in and through a Photovoice-based approach? In what ways social capital between people with different abilities could be advanced in and through Photovoice-based workshops? Photos and direct quotations of the participants have been used to clarify and support the presentation of research findings. The titles of the photos are given by the participants, and every picture is followed by the comments of the person who took it. Additionally, I blacked out any private information showed in the photos, like a license plate on a car, for ethical reasons. As mentioned before, the research was facilitated in Greek. Thus, all participants' comments are translated from Greek to English by the researcher. Words have power and in different languages they have diverse meaning. Therefore, I tried not to translate word-for-word, but to find the most appropriate words that give the specific meaning that participants want to. The findings are presented in the following main categories:

- Unveiling ableist and disablist assumptions and attitudes
- Making the invisible visible through participation
- The collective “us”

These categories were the key areas that the participants focused, captured, reflected on and found beneficial for understanding better the experiences of people with dis/abilities. These findings uncover the way ableism and disablism exist in society and propose ways about living all together interdependently and celebrating diversity of all people.

### 4.1 Unveiling ableist and disablist assumptions and attitudes

Critical theory invites people to challenge, deconstruct and unsettle negative assumptions about dis/ability (Vehmas & Watson, 2014, p. 639). Throughout this research project, there was a safe place for the participants to bring to light

collective misconceptions around dis/ability, challenge discriminatory attitudes towards dis/abled people, and reimagine the normal body. Through this process, they had an opportunity to understand deeper the experiences of people with dis/abilities and the social construction of dis/ability. Recognising ableist attitudes or ideas is important for every member in a community for many reasons. First, people are often unaware of the fact that their actions or words may discriminate and exclude others. The participants shared many stories that people's behaviour due to their ignorance, was unintentionally ableist. Moreover, unsettling stereotypes can be important for a person belonging to a minority group as a participant considered every opportunity to create representation and visibility to be very beneficial and a way to change values and ableist culture.

Changing a way of thinking and acting can be a long process. The first step is to clarify, recognise, and name the problematic situation. All topics discussed around ableist, disablist and discriminatory ways of thinking and acting will be presented. The photos by the participants sparked a lot of discussion along different themes that will be presented below.

### **Ableist inaccessible city**

As discussed in the conceptual framework, ableism refers to a way of thinking or acting that is based on an ideal standard of physical or mental ability. As Campbell (2009, p. 5) defines it, ableism is:

a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical, and therefore essential and fully human. Disability then is cast as a diminished state of being human.

In other words, ableism is any belief that disability is inherently negative and should be changed, cured or ameliorated.

The participants claimed that the denial of access rights is an expression of ableism. It signifies that there is one "normal" or right way of commuting. When a

whole city, like Athens, is designed in a way favouring one type of moving around and neglecting the needs of all individuals, it hinders the participation in the community for many people. This exclusion not only limits physical access but reinforces social isolation. It limits the opportunities for people to come together, interact, and possibly form relationships. The problem of inaccessible buildings, public transportation, and even public spaces was a major topic in this research project that always came to the surface. All participants agreed on how frustrating the way that the city of Athens where all live, makes people unable to move independently. This topic is well portrayed in the following photos (Photo 1, Photo 2 & Photo 3) by the participants and their related thoughts. These photos show inaccessible public and private spaces. Making all venues accessible is not a choice, but a commitment for inclusivity. More specifically, photo 1 shows a destroyed sidewalk in the centre of Athens, interrupted by other various barriers such as a trash bin and a road sign.

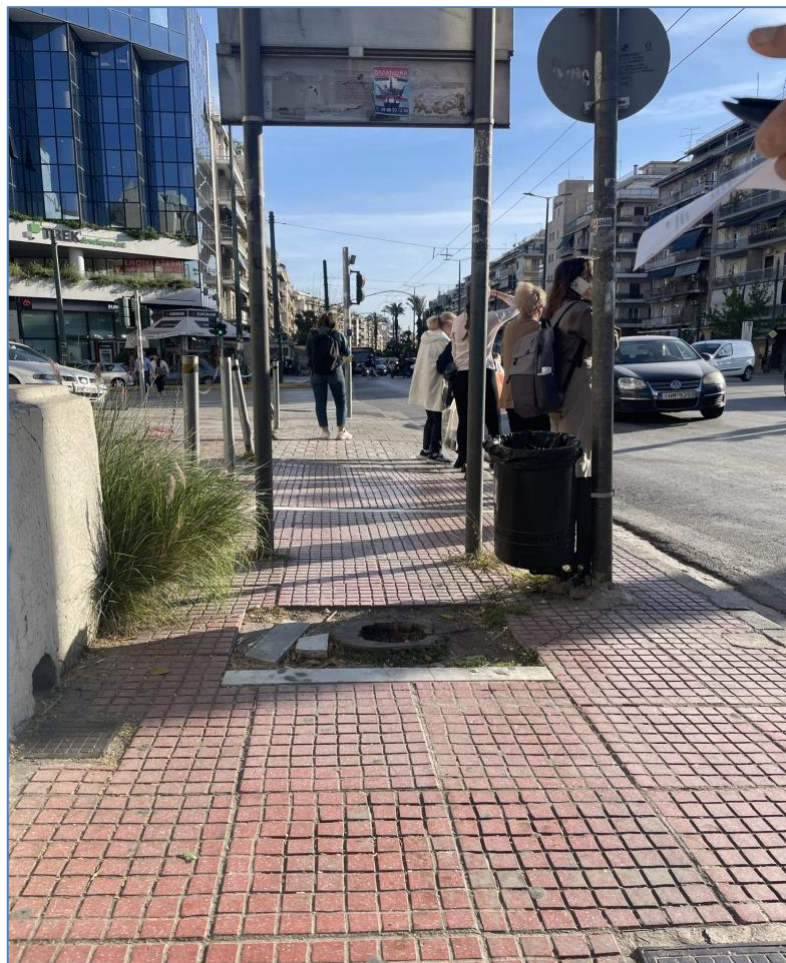


Photo 1. A destroyed sidewalk in the centre of Athens, a trash bin and a road sign

The title of this photo is ***Level Up: Athens' Game is over.*** While I was rolling, I saw this “art” piece in the center of Athens. I took this photo because when we talk about disability and barriers in Greece, this is what we mean. When people are afraid of becoming or being disabled, this is what they are afraid of. It was not easy but eventually I managed of passing through this uneven and broken sidewalk risking my own safety. (Participant B.)

The participants claimed that this is a common example of environmental barriers in Athens. The pathways for commuting are problematic and even sometimes hazardous. The characteristics of this pathway are the narrow, uneven sidewalks with no ramps or with destroyed ones that lead to nowhere. Moreover, the sidewalks sometimes have ramps with the wrong inclination and with stairs. These types of physical barriers challenge the safety of all, and especially of wheelchair users, who can have an accident and if they are alone, they may stay on the ground. Other examples of this issue are the next two photos (Photo 2 & 3). Photo 2 shows an entrance of a private building with a block of flats and photo 3 shows a broken ramp at an area in Athens.



Photo 2. A staircase entrance in block flats



Photo 3. A destroyed ramp at a neighborhood.

Participant E explained that the photos show two examples of inaccessible venues, one public and one private. In the first one (Photo 2), there is a building with apartments, and in the second one (Photo 3), there is a broken ramp located in a neighbourhood. He adds “this is frustrating because it prevents us or our friends from accessing places and meeting with each other”.

The participants questioned the transportation facilities too. They stated that the transportation infrastructure is an obstacle to autonomy and personal development. There are physical gaps between the stops and the vehicle floor, especially in buses. One participant claimed that she never uses the bus as she cannot commute independently by it. Apart from the existing gap, an inaccessible element that is a major obstacle too, is the broken elevators. Being able to use public transportation is a step towards self-development, as people have more chances to participate in community activities such as shopping, education, and employment opportunities. This topic is well pictured in the photo below (Photo 4) which shows participant B standing in front of an elevator in a metro station with a poster on it declaring that the elevator is out of use.



Photo 4. A girl user of wheelchair in front of an elevator. On the elevator there is a notice that it is out of use

The title of this photo is ***Houston we have a problem***. The elevators of some metro stations are always out of order, as their maintenance is avoided. This is so frustrating. Once, I had a conflict with an employee he denied helping me get on the metro. Therefore, I had to ask a stranger to help me. (Participant B.)

This phenomenon of inaccessible public transportation is also mentioned by participant C, who at the sight of the picture commented:

I get so upset when I hear in the metro an announcement that the elevators do not work. What if someone wants to go home and for them the metro is the only solution? The stations should have raising lifts in case the elevators are out of order. It is unacceptable that the stations are inaccessible. I do not use elevators, but I am an ally for anyone else who need them.

### **(Dis)ableist assumptions and actions**

Disability has continued to be constructed differently at different times (Ndlovu, 2021, p. 69). It is important to understand how disability has been and continues to be socially constructed in everyday life, as it affects the way disabled people are seen and treated. In a society where there are specific “normalcy” criteria, as it has been mentioned in the conceptual framework, people who fall outside the margins of this category have been called “disabled”. By constructing this “normal” group of people, society is designed for the functioning of this category

and creates barriers for anyone who does not belong to it. These barriers apart from physical as analysed before, are also negative perceptions and actions towards dis/abled people. As discussed in the framework, ableism is any perception that distinguishes the able-bodiedness as normal. Another phenomenon created close to ableism is disablism. Campbell (2009, pp. 3–4) defines disablism as “a set of conscious or unconscious assumptions and practices that foster the different or unequal treatment of people because of their actual or presumed disabilities”.

The findings indicate that false perceptions regarding dis/abilities tend to dehumanise people and make them feel as if they are excluded from the community. The social and cultural meanings given to physical conditions tend to create barriers to the interaction of people in a community. Dis/abled people tend to be seen as weak and in need of help. One participant noted that she has heard many times people feeling sorry for seeing someone in a wheelchair. These stereotypes need to be transformed as all agreed, because they only separate people from each other. Moreover, participants noted a range of discriminative, disablist practises in different settings of everyday life. These kinds of actions perpetuate social exclusion and marginalisation of dis/abled people. Dis/ability must be normalised. The next photo (Photo 4) comes to challenge a stereotype that wants dis/abled people not to have fun or not to participate in common activities, like going to the cinema. The photo shows participant B at an open-air cinema sitting comfortably on a chair (instead of her wheelchair) and using her wheelchair as a chair for her legs.



Photo 5. A girl at an open-air cinema, sitting at a chair with her arms behind her head and her legs on her wheelchair

The title of this photo is ***The alternative way to using your wheels.*** This is me, enjoying my time at an open-air cinema. Many individuals believe that disabled people do not do or do not want to do activities in the community, such as going to a cinema. The view of me watching the movie in this position may be weird for some people, but it is okay, I do not care. If you want to do something, you will always find a way. (Participant B.)

Participants talked also about the ignorance and stigma about invisible disabilities. Regarding the Disability Unit of the United Kingdom (2020) invisible disability is an impairment or health condition that is not immediately obvious. Few studies have shown the way persons with invisible disabilities face more challenges in the time they are called to disclose their hidden disability than those with more visible disabilities (Norstedt, 2019; Von Schrader et al., 2014; Wilton, 2006). For example, a participant explained this difficulty:

I have a friend with an invisible disability. She was forced to hide this information at her workplace because her disability would create a problem. This is tragic because, in case of an emergency, nobody would know what to do. She is fully functional and independent, but she still faces problems created by society. (Participant B.)

Additionally, there is evidence that there is still a great deal of stigma attached to dis/ability and sexuality (Addlakha et al., 2017, p. 4; Esmail et al., 2010, p. 1154; Parsons et al., 2017, p. 220). Participants highlighted different misconceptions about this topic. For example, one participant shared the fact that it is difficult for men to initiate a flirt with disabled women, either because they do not see them sexually or they see them only as sex experiments. In addition, some people are hesitant to initiate a romantic relationship with a dis/abled person, due to practical ignorance. As one participant noted:

I think the practical ignorance, not the theoretical, is the one to blame. I mean the ignorance people have because they do not get in touch with people who are wheelchair users or have some other dis/ability. This ignorance holds them back. For example, someone may be hesitant because they will wonder how they will go on a trip with that

person. Not having a practical experience of being around dis/abled people is the problem.

Furthermore, the signs of dis/ability sometimes lead to assumptions made about the other's sexual life. The ableist stereotypes portray dis/abled people as asexual, uninterested in intimacy or challenged to find a partner. This was shown by one participant who had taken a photo of a male wheelchair user at an erotic show (Photo 6) and the disablist comments that this view provoked. The photo below shows a man on a wheelchair taking a photo of a half-naked woman performing at a show.



Photo 6. A man user of wheelchair at a show, capturing a lady dancing

The title of this photo is ***Erotic Art***. This photo was taken because people with disabilities are often understood by society as being excluded from any kind of sexual activity, which is a misconception. I also overheard a man say that this man is videotaping this woman because he does not have a real partner. This comment shows that we are not educated at all regarding disability. I hope this picture will initiate a reflection around what we take for granted and a redefinition of our thinking. (Participant A.)

As has been noted by Shakespeare (2000, p. 163) dis/ability sexuality studies necessarily question ideas and values regarding sexual normality. People are

invited to challenge the narrow and limited notions of how to behave and look, rather than trying to conform and fit in the sexual stereotypes. He also highlighted that the critical elements for alternating prejudices around dis/ability sexuality will be not only changing the social response and cultural meaning but also illuminating the differences among people due to the nature or impact of their impairment. As a participant has shared, sexuality is different for each person as each type of disability is different and unique. Addressing this issue requires a cultural shift that challenges ableist stereotypes and educates people to prevent disablist practises.

Complementary to (dis)ableist misconceptions, participants revealed various ableist and disablist behaviours as well, in different environments. Two of them shared that they have witnessed forms of ableism in their workplace. As analysed in the framework, although many countries have legislation to affirm the working rights of people with disabilities, people continue to encounter ableism, social exclusion, and the worst exploitation. For example, one participant shared her concern when the company she worked for, hired a dis/abled person only to give the appearance of equality in the workforce. Moreover, one other participant said:

I had one colleague with disability and our supervisor always treated him differently. He was more tolerant of him. For instance, once our team was joking around while working, and our supervisor remarked everyone except for him. This is a separation that made my colleague feel like he did not belong in the group.

These two examples of behaviour indirectly discriminate people in the workplace. Nevertheless, participants mentioned behaviours of everyday ableism too. People put their needs first and at the same they do not care if their actions violate other's people needs and rights. When cars block ramps, they impact people's freedom to navigate safely in public spaces. They obstruct essential pathways for wheelchair users, individuals with mobility aids, and any other people relying on an accessible way to enter a sidewalk or a building. Addressing this issue, needs education, stricter enforcement of parking regulations and a collective shift of mentality for respecting the accessibility. For example, many people park their

cars either on ramps or on sidewalks, for their convenience. This oppressive practice needs to stop, as all the participants agreed.

This phenomenon is well captured in photo 7 that Participant C took. In this photo a car was trying to park on a ramp. The participant explained that she was trying to prevent the driver from parking there, but the driver was indifferent. In this way, she had to transform into a “snitch” and call the police.



Photo 7. A white car parking on a ramp illegally

The title of this photo is ***The indifferent and the snitch***. While the driver of this car was trying to park on the ramp, I stopped and informed her that parking on a ramp is illegal. Even though I explained to her that her action made the sidewalk inaccessible, the driver ignored me and gaslighted me. Therefore, I decided to call the police. This is a quick photo I took to remember the license plate. This illegal parking is a NO-GO situation. Do not park on ramps. (Participant C.)

The participants ignited a collective discussion and reflected on the importance of language. While one speaker suggests that actions matter more, and that

words are not that important if the intention is good, two others came to disagree claiming that words make a difference. Some words (re)produce ableism and different forms of dehumanisation. They claim that many terms are used and manipulated to create narratives that have the power to shape individual and collective ways of thinking and acting. An example shared was the outdated terminology “people with special needs” which is a radical discriminatory wrong use of language. The participant claimed that there is not a special need, the need is the same but the way for its cover differs. For instance, the need for food is the same, the fact that alters is that someone may be able to use a fork, and others may need different equipment to eat. The importance of avoiding outdated terminology and instead using welcoming and inclusive language was reported to be very crucial by one more participant. The way people talk about dis/ability reflects how and what they think about it. “There is no thinking without language”, as participant C stated. What is more, the use of outdated terminology is a sign that people are still uneducated about dis/ability even for the basic ethically correct way of talking about it.

To conclude, I can state that breaking misconceptions and attitudes related to dis/ability was an important motivator for the participants. By letting mistaken ideas or actions come to light, they realised the way the ableist society creates dis/ability and its consequences. Furthermore, it was meaningful for recognizing their own questions around dis/ability, getting answers and consequently understand better the experiences of people belonging to their society.

#### 4.2 Make the invisible visible through participation

Trying to include a minority group in the broader community can be challenging. Wanting to understand better what it can be done to break all these misconceptions mentioned before, the participants gave attention to the visibility of all members of society. They agreed that providing opportunities for engagement is beneficial because if people are exposed to the appearance of the “different” or “un-common”, they eventually become more familiar with it. From theory, social participation has been recognised to play a significant role in

promoting social inclusion (Cordier et al., 2017, p. 4). The participants then referred to ways that actively involve and engage individuals in a meaningful way towards inclusion.

First, they identified arts as a medium that can possibly shape and reflect identity, raise the visibility of marginalised communities and bring people together. They make it clear that certain types of art and creative activities can be exclusive as they may problematically represent minority groups and unethically address dis/ability topics for financial reasons. Nevertheless, inclusive arts can challenge stereotypes, spark discussion and connect people together. As a participant shared, she has never seen a dis/abled actor/ress playing a role that does not have a connection to their type of dis/ability in a Greek theatre or Television show. Public appearances of people with dis/abilities in performances or films, playing roles unrelated to their impairment, reinforce their societal inclusion and value. In contrast, their absence contributes to the invisibility of people with different abilities. They also agreed that famous artists created visibility through their work and challenged stereotypes, like the famous classical music composer Ludwig van Beethoven, or the well-known artist Frida Kahlo.

Besides arts and creative mediums, participants mentioned the importance of educating children and creating for them an environment that recognizes, and respects diversity of all people. Family and school are the first responsible for fostering this kind of environment. Parents should educate children about dis/ability and normalise seeing or being around people with different abilities. At the same time, being in a school where the teacher talks open about dis/ability or the teacher is dis/abled themselves, would really be beneficial. All the participants agreed that dis/abled people should participate and have equal chances for having professions like the one of a teacher if they want to. This would be a positive change for everyone in a community. For example, children would normalise being around people with different abilities and would be more familiar to dis/ability and dis/abled people would have more choices for equal participation.

In creating visibility, participants agreed that occasional trainings and educational speeches are not enough. For instance, a participant claimed that every International Disability Day she is invited to schools to talk to the children about her life and her experiences. However, she stated that this is not enough. People with dis/abilities must have equal chances for representation and participation. Ensuring that all people, whether dis/abled or not can fully participate in the community is very important. If they participate equally in a community, dis/ability will be normalised and therefore no one will have to be educated, or aware. This is showed in Photo 8. The participant captured a sign language interpreter at a music concert, converting the lyrics of the songs into signs.

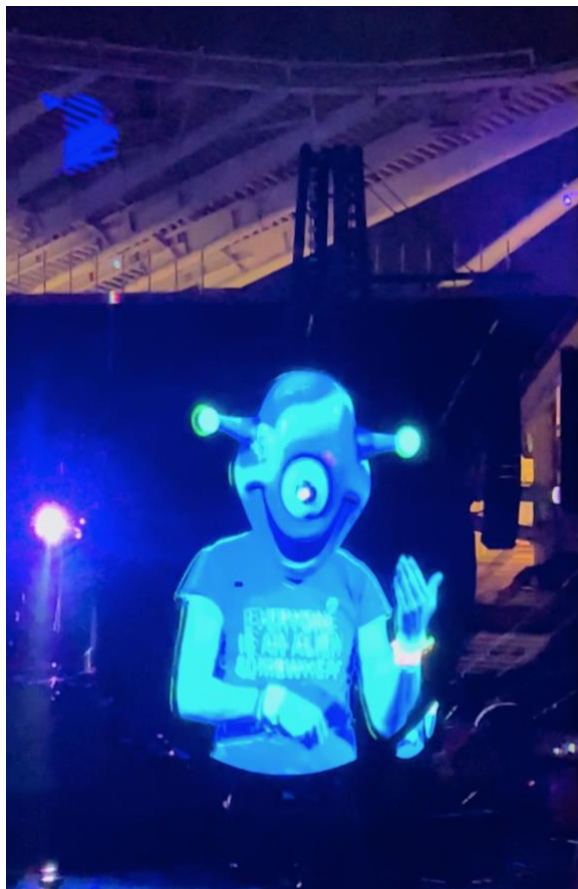


Photo 8. A person wearing an alien mask at a music concert converting the lyrics of the songs into signs

“I took this photo at a music concert. I was happy that there was a sign language interpreter, as it made the performance more inclusive. This is a sign of a society that respects all individual’s traits and characteristics.” (Participant E.)

In conclusion, any form of true engagement is a step towards visibility and inclusion. Forming an environment where all people have the same opportunities to participate and be visible, is a step towards inclusion. Arts and creative activities can be allies in this fight, while family and school have to form the new generation.

### 4.3 The collective 'us'

As described in the conceptual framework, dis/ability is not an individualistic trait but concerns everyone in society sooner or later (Dolmage, 2017). Equal participation for all must be a collective concern as it plays a critical role in the realisation of human rights for dis/abled people. This participation is shaped by various factors, including structural and environmental elements related to accessibility as mentioned in the previous subchapter, and support for community engagement. Being a member of a community requires existing as the collective 'us' rather than as 'them' or 'other'. The social capital theory recognises the importance of social networks that encompass shared values, such as trust and reciprocity, and can potentially promote cooperation and collective action (Agampodi et al., 2015; Lin, 2001; Tsounis et al., 2023). Only when people think and act collectively, they can have success for all. But how can people think collectively when they do not know the needs of other members or sometimes when they even ignore their existence in the world? If people come together and form connections, they can engage in meaningful conversations, share information and think toward common goals.

From the comments of the participants, it appears that collective thinking is important to create a more inclusive environment for all people. For example, participant B shared that some people park their cars on the ramps without thinking the other's needs. In this case, even though there is a barrier free environment, the members of the community create one barrier due to their ignorance. This is well portrayed in photo 9. Participant A pictured the ticket she got because she parked in a forbidden space making the sidewalk inaccessible.



Photo 9. A ticket for illegal parking

The title of this photo is **The penalty**. It is a fine imposed on me and in fact a reminder of my individual responsibility or... irresponsibility. The fast pace of the urban environment can lead people to act without empathy. We must learn to recognize our individual responsibility even in dysfunctional contexts. We must think collectively. (Participant A.)

The findings based on the data analysis revealed the importance of collective thinking for creating an equal community. The realisation of this community, that enables all people to have equal opportunities, resources, and rewards, depends on community members valuing each other's diversity. In other words, inclusion arises when a community acknowledges that its identity is shaped by all its members' differences and similarities. As one participant mentioned, "inclusion is not about getting to know the 'other', and raising awareness about the 'different', it is more about engaging and realising that we are all different in a way and that is beautiful". This idea is well expressed in Photo 10 in which participant C captured two fruits from different sides. Through these different sides, she wanted to suggest a way of understanding our co-existence.

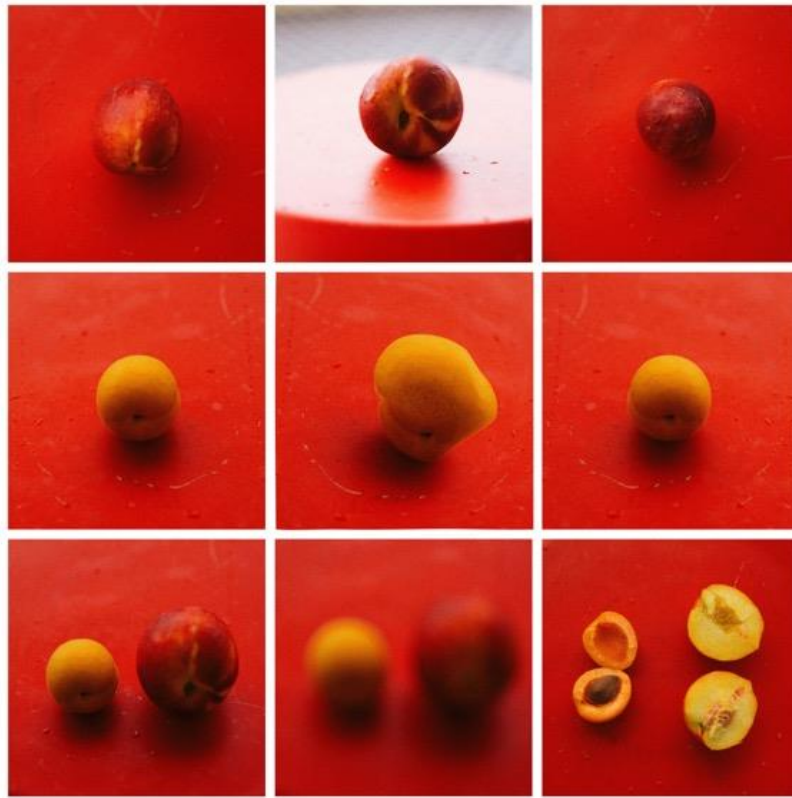


Photo 10. A set of nine pictures capturing one nectarine and one apricot from different angles and angles

The title of this photo is ***How to be a fruit***. Both fruits are different. Different colours, different sizes and shapes. Different skin, texture and taste. But both are still alike. They are both fruits. They are both refreshing and sweet. Both healthy and soft. Two fruits can be different and similar at the same time. There is not a right or a normal way of being fruit. This is an allegory of the human body. There is not a normal body. If people are exposed to the view of different bodies and people, there is a better chance for inclusion. (Participant C.)

To summarise, collective thinking is an important element for fostering a more inclusive environment for all. Strong relationships between people of different abilities in a community make collective thinking and action easier for groups.

## 5 Conclusions and discussion

In this chapter I present the final conclusions of the research based on the findings. Thoughts around Photovoice technique are also discussed, and the trustworthiness of this research is elaborated. I also propose future directions for research and practice.

### 5.1 Conclusions

The research answered the questions: What kinds of experiences of ableism and disablism can be recognised in and through a Photovoice-based approach? In what ways social capital between people with different abilities could be advanced in and through Photovoice-based workshops? As mentioned in the introduction, “Visibility of dis/ability” is a research project aiming to bring people with different abilities together, engage in one common creative activity, interact and possibly form social capital. The key aspects of the research task were to ensure people’s right for self-representation and to tell their truth, and at the same time give the chance to other people belonging to the community to learn about their experiences. Through the Photovoice approach, participants had the chance to capture their reality, document it and share it with each other. In addition, through its publication, this research may work as a motivator for other professionals in the cultural wellbeing field and beyond to consider the experiences of dis/abled people and motivate them to do similar projects.

The findings uncovered a range of experiences on how ableism and disablism manifest in everyday life by people with different abilities. Their experiences include examples from structural inequities to (dis)ableist ideas and practices, and thoughts about creating a more inclusive society for all. More precisely, the analysis of the data showed how the mechanisms of ableism and disablism are expressed in people’s assumptions and actions. Ableism was identified in the whole urban structure of a city that enables mainly ableist ways of being and commuting. Ableist assumptions and actions were also witnessed by various participants with different abilities in different settings of their everyday life, like in

the workplace or at a festival. These discriminative ideas and actions tend to marginalise and dehumanise dis/abled people. Thus, ableism and disablism set barriers to equal participation and celebration of people's diversity in a society. In contrast to ableism and disablism, the participants reflected on ways to celebrate diversity. Social participation has been identified as an essential element in fostering social inclusion (Cordier et al., 2017, p. 4). The findings of this research proposed participation as a way to give visibility, normalise dis/ability and deconstruct ableist ideas of "being" in the world. The findings have shown also the importance of thinking dis/ability as a collective matter. Although dis/ability is ubiquitous, the experiences of disabled people are continually translated as individual's concerns (Mollow, 2017, p. 340). Everyone will experience at some point in their life some kind of dis/ability. Collective solidarity, interdependence and mutual respect are necessary for recognising that dis/ability is not an individualistic trait that concerns only the people who have it.

The findings suggest that this study was helpful and beneficial for enhancing understanding concerning the experiences of dis/abled people. The response from the participants was very positive concerning their participation. One participant claimed that the discussions between the participants were very enlightening, and she realised that discussions around dis/ability and society must be included in public debates. All participants agreed that the sharing of lived experience stories from those involved and whose lives are at the center of the problem was very helpful and important. The analysis of the data also shows that the presence of people with dis/abilities in the research, and the opportunity to represent themselves was a significant element for understanding better their experiences.

At the beginning of the research, it was obvious that some participants were unfamiliar with disability related topics. For instance, some of them had never met a disabled person before, and they had various questions or wrong assumptions about how is living with an impairment. Their use of language and terminology was also outdated. However, in the second meeting, a change was noticed even in their language. They did use their words very wisely and used "politically

correct” terminology. Moreover, they seemed to have a deeper understanding of the societal obstacles that disabled people face in their everyday lives. Through their pictures and their comments on them, it was obvious that they were advocating for accessibility and promoting a more inclusive community through participation.

The duration of the data construction period was relatively short, just two meetings of two hours each and the independent creative project in between. I understand that this time is short for developing social capital between the participants, and I did not set any specific aim for its realisation. Nevertheless, through the research and the findings, I noticed that this kind of research can potentially encourage the formation of social capital between people with different abilities. According to Putnam (2009), interaction and social capital are most likely to develop among people who have common interests, backgrounds, education and social status. Between bonding and bridging social capital (Putnam, 2000, p. 22), this research project seems to include a combination of those. On one hand, the research project was based on a creative approach and promoted bonding social capital through sharing similar interests (like photography). On the other hand, it was an opportunity to bridge social capital and connect people with different abilities and backgrounds. The research promoted interaction between relatively diverse members of society. People with different abilities, but with the same interest in creative and art-related approaches, came together, interacted, learnt from each other, and broke stereotypes. Especially, in the second meeting the participants built an atmosphere where everyone was respected, encouraged to express themselves, transparently exchanged ideas and felt welcomed. Therefore, similar research programs can possibly supply social capital.

Another key element of the study was not only the arts-based approach used for the construction of data (the Photovoice), but also the creative group activities used for promoting interaction between participants. When people join creative group activities, their interaction is facilitated, and they are more open to influencing this interaction but at the same time be influenced by it (Huhtinen-Hildén & Isola, 2019, p. 10). Indeed, when people join one creative activity, they

come together, interact, regulate their emotions and connect with each other. Additionally, creativity has been associated with social inclusion. Participation in arts related activities was seen as an effective medium for promoting well-being and social inclusion (Wilson et al., 2017, p. 8). Therefore, participating in arts-related and creative activities is also a human right. Specifically, everyone has the right to participate in the cultural life of community as set out in Article 27 of the Universal Declaration of Human rights (UN). During the project, creativity played an important role for enhancing participants' engagement and their in between relationship. Therefore, I can state that creativity has potentially a positive impact on the process of bonding and bridging social capital. Moreover, culture and health or well-being are seen to be related. The value systems, the traditions and the beliefs of a community affect the way they define health and well-being (Napier et al., 2014). Therefore, there is a diversity in which health is contextualised, and can be better understood through culture as meanings are conveyed through arts and culture. Napier et al. (2014, p. 1607) state that "a failure to understand the intersection of culture with other structural and societal factors creates and compounds poor health outcomes, multiplying financial, intellectual, and humanitarian costs". The relation between culture and health holds the hope for humankind (Napier et al., 2014, p. 1634).

## 5.2 Reflections of the impact on the Photovoice technique

The Photovoice is drawn by the Freirian thinking (1970) and it can have various benefits as a medium when facilitating a workshop in the community. Photovoice is a method that enables people to document their reality through photos, reflect on their concerns and potentially lead to social change by influencing policies (Wang & Burris, 1997, p. 373). One participant reported that she valued hearing about other's experiences and getting informed about dis/ability, as she did not have any opportunity to interact with disabled people before and learn from them about their experiences. Their pictures were a powerful means to visualise their experiences and make them more visible and comprehensible. In this way, by the end of the Photovoice, everybody agreed that it was a very enlightening, helpful, and eye-opening process.

Furthermore, as Photovoice uses photography and dialogue, it gives agency to the participants for collaboration and engages them throughout all the process (Rania et al., 2019, p. 11). The participants expressed positive comments regarding their contribution to the Photovoice. They expressed also excitement and anticipation for presenting or seeing the pictures of others. Additionally, their visible enthusiasm was noted throughout the whole process while commenting, sharing, and observing all the pictures.

Finally, Wang and Burris (1997, p. 372), mention the benefits regarding participants' networks and relationships. This project created a brave space and opportunity for these three participants to meet and come together. Throughout this process, they shared their personal life stories, critically discussed the societal face of disability, and highlighted not only differences but also similarities in their life. When the research ended everybody agreed to exchange social media and keep in touch. As I was informed, because of being in the study, one participant wanted to collaborate professionally with another participant and interview her. Moreover, after the research, a group chat was created, and all the participants shared their intention to meet in person. Meeting with all these beautiful people was an empowering experience.

### 5.3 Trustworthiness and future implications

This research has its limitations. One of the limiting factors of this study is the fact that the disabilities of the participants were physical. In other words, people with other kind of disabilities were not included. In disability research people with learning disabilities are often not included in the process because of their unique and often nonverbal way of communicating (Lester & Nusbaum, 2018; Mansell, 2010; Vorhaus, 2016). Before analysing this idea, I must justify the chosen terminology. The term 'learning disability' has been used more often in academia and at the same time it has been recognised among people with and without learning dis/ability for many years (Gates & Mafuba, 2016). Nevertheless, every individual has the right to be called as they prefer. Thus, if I would include people

with learning disability in research I would follow their own preference in terminology.

It is important to find new ways to include all people in the production of knowledge. The importance of including them is not only focused on the academic outcomes but on the process findings too (Walmsley et al., 2018, p. 757). The process of the research can foster the empowerment of people with learning disabilities by actively engaging them in collaboration. Doing inclusive research demands more financial resources and flexibility in time (Wamsley et al., 2018, p. 757). Therefore, for being able to include people with different levels of performance, I would have needed more time and financial support.

Additionally, intersectionality gets more and more attention in dis/ability activism (Evans, 2022). The way in which dis/ability can be analysed in correlation with other forms of oppression like race, gender, social class results in recognizing intersectionality in the study of dis/ability. Intersectionality invites people to understand dis/ability in relation to other forms of social inequalities. In this way, it crystalises that this is a task for those supporting dis/ability rights movement (Evans, 2022) and will help academics understand people's experiences better by recognizing all the social identities they can hold. Hence, including in research immigrant disabled people or disabled belonging to the LGBTQAI+ community is significant for making it more inclusive.

Another limitation of the study was the last-minute withdrawal of two participants due to their stressful everyday life and a last-minute change in their schedule. I recognise that this change can potentially bring an imbalance in the interrelationship dynamics between the members. Nevertheless, as the participants had only met once before the two withdrawals, there was not such a big difference in their interaction. If the timeline of the research was longer, then I would ask the participants to be always present except for specific emergent occasions.

If I would do this research again, I would plan some meetings in person too and I would recruit more participants to create small groups of people. I would use the Photovoice technique again but with some changes. I would equip all participants with professional cameras, and they would have a photography course to get to know how to use them. In addition, except of taking pictures of their own everyday life, it would be valuable to picture in pairs the environment of each other. In this way, they would dive into the world of each other and acknowledge by first hand their experiences.

More research could be done to explore how different kinds of creative activities can be a medium to create social capital between people with different abilities. It would be interesting to organise a creative toolbox with inclusive activities for groups of people with different abilities. Additionally, including people in the whole research process and actively engaging them has become a central component of the disability rights movement's ambition 'Nothing about us, without us'. When researching a dis/ability related topic, I would examine using the concepts of ableism, critical dis/ability studies, and dis/ability. I would also use concepts of participation and engagement, as the concept of inclusion, brings to the surface the concept of exclusion. Moreover, when researching individuals' experiences, it is problematic to refer to the concept of inclusion, as inclusion is more societal and concerns more the structural policies. It would be beneficial to look at the spot of organizations and policies for promoting inclusive actions.

There is a growing interest in culture concerning dis/ability from a critical perspective of view, examining dis/ability from the perspective of the social model rather than of the medical one. For example, the Pavilion of Finland in 2024 at the 60<sup>th</sup> International Art Exhibition- La Biennale di Venezia, was a collective project where visitors were encouraged to (re)assess societal expectations. *The pleasures we choose* was a multifaceted collaboration of three artists for whom art, life and activism are intertwined and their inspiration is from their experiences of structural, environmental and social imbalances. It is a call for everyone to reimagine the world and transform the ableist cultural attitudes.

Another research project related to dis/ability with a critical perspective is *Disability and Dignity* (2021–2025) by the University of Eastern Finland. This project aims to review the assumptions of the legal system concerning dis/ability and dignity and explore how the policies impact the everyday life of disabled people. In other words, this project will gain deeper insights into how the law either reinforces or reduces the marginalization of disabled. By questioning and analyzing the assumptions of dis/ability within legal frameworks, the way laws impact disabled people's lives can be explored. This approach is valuable because it moves beyond the challenges faced by disabled individuals and seeks to understand how these challenges are influenced or created by legal systems.

Inspired by these two projects, my future proposals for dis/ability research should prioritize inclusive methodologies working with people with different abilities to explore people's assumptions regarding ability and examine how these affect the interaction between people with or without dis/ability. This project through creative practice designed for all people regardless of ability, would create a space for challenging the dominance of the "normal" body, viewing all bodies as equally respected and getting into contact with them. Hence, people with different abilities would have the chance to engage in creative common activities and overcome possible limitations that burden their interaction.

Only when everyone is thinking collectively will the world really change towards equal participation. I have a dream...that in the end knowledge will show the way how to creatively live all together, no matter of abilities and medical diagnosis.

### **Acknowledgements**

I cannot avoid thanking all the people that contributed in their unique way to the realisation of this research. First, I acknowledge and thank the participants of this research that trusted me and followed me into this research project.

Moreover, I would like to thank my amazing advisor Sanna Kivijärvi for always inspiring me, encouraging me and gently guiding me throughout my research.

Lastly, I want to thank all my wonderful teachers, fellow students, and especially Heidi and Katri, who became my very good friends. Undoubtedly, my last warm thank to my family for supporting me to this journey and even more to my sister Anneza for being there when nobody was.

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## Appendices

### Appendix 1: Participation Information Sheet

#### Participant Information Sheet

##### **PARTICIPANT INFORMATION SHEET**

**Study title:** Visibility of Dis/ability

##### **Invitation to participate in a research study**

I would like to invite you to take part in this qualitative research study that is focused on creating a social capital between people with different abilities. The aim of the study is to analyze how a creative method can be a medium for raising awareness of people about the needs and experiences of dis/abled people. We are meeting online in June two times. The group will consist of the responsible researcher (Xanthippi Panagiotou) and 3-5 participants. The meetings will be in English or Greek (depending on the participants).

This information sheet describes the study and your role in it. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with me if you wish. If there is anything that is not clear, or if you would like more information, please ask me. After that I will ask you to sign a consent form to participate in the study.

##### **Voluntary nature of participation**

The participation in this study is voluntary. You can withdraw from the study by informing me at any time without giving any reason and without there being any negative consequences. If you withdraw from the study or withdraw your consent, any data collected from you before the withdrawal can be included as part of the research data.

##### **Purpose of the study**

The purpose of this study is to discover how a creative method can be a medium for raising awareness of people concerning the needs and experiences of dis/abled people. It's time to find new ways of live all interdependently together and acknowledge others' people experiences. That's why people with different abilities will participate and through the method of the Photovoice they will share their experiences.

##### **Who is organizing the research?**

The research is a part of my, Xanthippi Panagiotou, Master's Degree studies at Metropolia University of Applied Sciences of Helsinki in Finland. The Master's Degree programme is called "Creativity and Arts in Social and Health Fields" (CRASH).

##### **What will the participation involve?**

We are meeting two times online via Zoom and one meeting will be 2 hours long (4 hours in total). Breaks will be set by the participants and the dates of the meetings will be in June. The method for data collection that we will use is the Photovoice. The participants will be asked to express their points of view or represent their communities by photographing anything significant to them related to inclusion, accessibility, participation, and connectedness. By utilizing these pictures, respondents can reflect upon and explore the reasons, emotions and experiences that have guided their chosen images. During the meeting we will discuss the participants' experiences about the related topics. The discussions will be recorded and will be used by the researcher as a

## Participant Information Sheet

material for the study and will be deleted together with the other data. Pictures will be used as data too and some of them will be published in the paper after the consent of the owner.

**Possible benefits of taking part**

The participants can contribute to the creation of knowledge around dis/ability and raise awareness concerning how the society creates dis/ability, inclusion, and connectedness. Moreover, it can be a reflective experience that helps the participants to gain self-awareness, challenge assumptions, and broaden perspectives.

**Possible disadvantages and risks of taking part**

There is a risk that published pictures may be copied and/or used the original study agreement.

**Financial information**

Participation in this study will involve no cost to You. You will receive no payment for Your participation.

**Informing about the research results**

The aim is to submit the Master's Thesis by the end of 2024. After the thesis is ready, I will send it to all the participants. The thesis will be written in English. The names of the participants will not be mentioned in the thesis or in any other situation if they do not wish for it.

**Termination of the study**

The researcher of this study can also terminate the study if there are major problems with the participants that cannot be solved.

**Further information**

Further information related to the study can be requested from the researcher / person in charge of the study.

**Contact details of the researchers**

Researcher / Student

Name: Xanthippi Panagiotou

Tel. number: +30 6936938120, +358 465399405

Email: Xanthippi.Panagiotou@metropolia.fi

Person in charge of the study / Supervisor

Name: Dr Sanna Kivijärvi

**Appendix to the Participant Information Sheet: A Privacy Notice for Scientific Research**

Within this study, your personal data will be processed according to the European Union General Data Protection Regulation (679/2016) and current national regulation. The processing of personal data will be described in the following items.

**Data controller of the study**

Data controller is the natural or legal person, public authority, agency, or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data.

Student (Xanthippi Panagiotou)

**Types of personal data that will be collected**

Name, email address and a phone number to be able to contact the participants. The meetings will be recorder for the purpose of data collection.

There is no statutory or contractual requirement to provide Your personal data, participation is entirely voluntary.

**Legal basis of processing personal data**

A consent granted by the data subject.

If the legal basis is a consent granted by the data subject, you have the right to withdraw the consent at any time as described in this Privacy Notice.

**Nature and duration of the research (how long will the personal data be processed):**

One-time research                       Follow-up research

Duration of the research: 1.3.2024-31.12.2024

**What happens to the personal data after the research has ended?**

How the personal data will be processed after the research has ended:

- Any research materials containing personal data will be destroyed
- Any research materials containing personal data will be archived
  - without identifiers
  - with identifiers

Where the materials will be archived and for how long:

**Data transfer outside of research registry:**

Your data will not be transferred outside of research registry.

**Possible transfer of personal data outside the EU or the EEA:**

Your data will not be transferred outside of the EU or the EEA.

**Your rights as a data subject**

Because your personal data will be used in this study, you will be registered to study registry. Your rights as a data subject are the following

## Appendix 2: Participation Consent Form

Participant Consent Form

### PARTICIPANT CONSENT FORM

**Title of the study:** Visibility of Dis/ability

**Location of the study:**

Researcher/ Student:

Name: Xanthippi Panagiotou

Tel. number: +30 693 693 8120, +358 46 53 99 405

Email: [Xanthippi.Panagiotou@metropolia.fi](mailto:Xanthippi.Panagiotou@metropolia.fi)

Person in charge of the study/ Supervisor

Name: Dr Sanna Kivijärvi

Name of the organization / Faculty: Metropolia University of Applied Sciences

Email: [Sanna.Kivijarvi@metropolia.fi](mailto:Sanna.Kivijarvi@metropolia.fi)

I \_\_\_\_\_ have been invited to participate in the above research study. The purpose of the research is to analyze how a creative method can be a medium for raising awareness of people about the needs and experiences of dis/abled people.

I have read and understood the written participant information sheet. The information sheet has provided me sufficient information about above study, the purpose and execution of the study, about my rights as well as about the benefits and risks involved in it. I have had the opportunity to ask questions about the study and have had these answered satisfactorily.

I have had sufficient information of the collection, processing and transfer/disclosure of my personal data during the study and the Privacy Notice has been available.

I voluntarily consent to participate in this study. I have not been pressurized or persuaded into participation.

I have had enough time to consider my participation in the study.

I understand that my participation is entirely voluntary and that I am free to withdraw my consent at any time, without giving any reason. I am aware that if I withdraw from the study or withdraw my consent, any data collected from me before my withdrawal can be included as part of the research data.

**By signing this form I confirm that I voluntarily consent to participate in this study.**

**If the legal basis of processing personal data within this study is a consent granted by the data subject, by signing I grant the consent for process my personal data. I have right to withdraw the consent regarding processing of personal data as described in the Privacy Notice.**

**Date**

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Signature of Participant

Participant Consent Form

The original consent signed by the participant and a copy of the participant information sheet will be kept in the records of the researcher. Participant information sheet, privacy notice and a copy of the signed consent will be given to the participant.

## Appendix 3: Consent form for picturing other people

### CONSENT FORM

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You are invited to have your picture taken by one of the photographers involved with Photovoice Visibility of Dis/ability. Photovoice Visibility for Dis/ability is a research study and the researcher is Xanthippi Panagiotou. The purpose of the research is to analyse how a creative method can be a medium for raising awareness of people about the needs and experiences of dis/abled people.

Photovoice has four goals:

1. It helps people to record and think about their community's strengths and problems.
2. It identifies important issues through group discussion and photographs.
3. It gets the attention of politicians and other decision makers.
4. It works toward positive change in our community.

Pictures taken in Photovoice will be shown to the other participants in order to create awareness. Some of them, they may be published in the research paper after discussion and agreement with the photographer. Others viewing the pictures may recognize you, but there are no names or contact information. Photographs will not be used to make money. Please sign this form if you agree to have your photograph taken by a participant of Photovoice. If you would like a copy of the photograph taken of you, please write down your address:

Date \_\_\_\_\_

Subject Name \_\_\_\_\_

Name of Photographer \_\_\_\_\_

Signature \_\_\_\_\_