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I HAD TO FIT INTO THIS WORLD THAT WAS NOT BUILT FOR ME

An exploration of disability expertise in relation to the social mobility of young disabled people in The Netherlands

Master Thesis for the program Cultural Anthropology & Sustainable Citizenship

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“I had to try to adapt. I had to fit into this world that wasn’t built for me.” – Jimmy Lebrecht

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Introduction

During a night in the second month of my fieldwork, I opened my laptop, sat down at my kitchen table, and did not take my eyes of the screen for almost two hours straight. I was watching a documentary called Crip Camp.

Firstly, it tells the story of camp Jened, a summer camp in America where disabled youngsters could fully express themselves, unite, share experiences and learn together. The skills and values they learned in that camp formed the foundation of a radical disabled activist group: Disabled In Action. This group later managed to occupy a governmental building and stay inside for over 23 days through the skills, connections and knowledge they gained largely at camp Jened, as well as through their shared experiences as disabled people moving in the world. When the FBI cut off communication technology, people with hearing impairments used sign language to communicate through the windows with the outside world. When the design of the city streets blocked their movement, they blocked the streets with their bodies and wheelchairs. When society did not listen to them and segregated them, they listened to each other and unified.

Towards the end of the documentary I got a lump in my throat and tears started running down my face. The scene I was watching at that moment showed crying, sighing and screaming disabled people crawling up the stairs of the American Congress building. While crawling up the stairs, some of them dragged their crutches and wheelchairs behind them. The voiceover said: "We, as disabled persons are here today to ensure […] the ordinary daily life that non-disabled Americans too often take for granted; the right to drive a bus or a train, the right to any job for which we are qualified, the right to enter […] any public accommodation. We will no longer accept the denial of equal opportunity". The disabled people crawling up the majestic stairs did not seem weak to me, instead I saw they were full of determination, capability, and knowledge.

Camp Jened was organized during the '60's. The scene I just described took place in the 90's. "This camp changed the world, and nobody knows this story" says one of the activists Jimmy Lebrecht at the start of the documentary. And there I sat crying at my kitchen table in 2020 because it struck me that my participants were still facing the same struggles and were using the same techniques to establish and demand similar changes. They too were conquering physical and social barriers by grouping together and using their power and knowledge gained through the experience of disablement to establish an equal place in society. That is why the powerful stories of disabled people should still be told and heard today.

This thesis features some of those stories. I invite you to read them and gain a deeper understanding of what it means to establish your place in a physical and social environment that is, up to this day, not accommodating bodily difference.

A lot of scholarly attention has been given to the ways in which people with disabilities are "*systematically dispossessed, incarcerated, injured, impoverished, disenfranchised, denied legal voice, abused and neglected*" (Hartblay 2020, 27). People with disabilities are faced with persistent ableist norms that create social and physical barriers that ultimately leads to their exclusion in the parts of society other able-bodied members participate in constantly (Titchkosky 2011). This exclusion shows itself in the high absence of people with disabilities in education, employment and public space (World Bank 2019; Titchkosky 2011; Hartblay 2019; Jaffe 2015). The approach that foregrounds the ways in which disabled people are limited in their mobility, access and participation has been dominant in the current scholarly debate on disability. However, Hamraie and Fritsch (2019) argue that disabled people are active experts and designers of daily life. Additionally, Hartblay (2020) calls for ethnographic attention of a particular knowledge that she labels "disability expertise"; "the specific knowledge that disabled people develop and enact about unorthodox configurations of agency, cultural norms, and relationships between selves, bodies and the designed world" (Hartblay 2020, 26). This attention is crucial to analyze and gain a better understanding of how disabled persons mobilize power in different cultural contexts and omnipresent systems of ableism (Hartblay 2020, 27).

With this thesis I respond to this call and aim to add to the existing literature by looking at the ways in which young disabled people in The Netherlands use disability expertise to establish social mobility in a world that is based on ableism.

Theoretical context and position

According to Dalakoglou (2012) mobility is one of the most defining elements of the human condition in our current times. He also noted that, connected to the importance of mobility in our lives, immobility can easily become a source for exclusion (Dalakoglou 2012). Additionally, in the academic debate around mobility, many researchers agree that spatial mobility is also highly influential for the way social lives are shaped (Jaffe 2015; Cresswell 2010; Titchkosky 2011). Furthermore, it is known that physical mobility is associated with social mobility. The places we go to and the ways in which we move are influential for how we are perceived by others as well as how we perceive ourselves (Jaffe 2015; Cresswell 2010)

Since the accessibility of places is oftentimes different for disabled people, together with the fact that they oftentimes move differently than able-bodied peers led me to dive deeper into the connection between social and physical mobility in relation to disability.

Disability anthropology

To understand and interpret this research correctly, it is crucial to define the way disability is looked at in this research. Disability is commonly defined as a chronic impairment that has a significant impact on someone's daily life, causes abnormality and a need for medical care (Kumar 2016). But this medicalized approach that focusses on impairment neglects important part of what it means to be disabled. I therefore choose to follow Hartblay (2020), Titchkosky (2011) and Kumar (2016) here who state that disability is a complex category with culturally contingent and social implications (Hartblay 2020, 26) that causes friction between an individual's physical capacities and his/her material and social environment. It is thus argued that it is primarily the environment that leads to disablement, rather than seeing disability as a fixed condition. The cultural and social meanings attached to disability make it an interesting field of study for sociocultural anthropologists, and they have a long history of doing research on this topic (Hartblay 2020). Their work has had a significant impact on the development of critical disability studies (Kasnitz 2020). Although anthropological interest in disability is rising from the beginning of this century, Kasnitz (2020) argues that anthropological institutions and bureaucracy have remained profoundly ableist. This is illustrated by the idea that disability anthropology is often believed to belong in the realm of medical anthropology or misread as mostly being valuable as applied anthropology (Kasnitz 2020, 17). Contrastingly, disability anthropologists actually have the capacity to contribute theoretically to the study of disability through their ethnographic accounts (Kasnitz 2020; Hartblay 2020). Goggin (2016) argues that critical accounts of disability can make a substantial contribution to a rich and promising research field that combines disability studies and mobility research. According to Goggin (2016), this approach has a lot of potential for gaining a better understanding of fundamental aspects of human beings, social arrangements and environments. Additionally, approaching disability in an ethnographic way that foregrounds social and cultural aspects by accounting for the lived experiences of disabled people, it can contribute to the demedicalization of this research field (Kasnitz 2020). As a cultural anthropologist and researcher in the field of disability, I align myself with the position of Goggin, Kasnitz, Titchkosky and Hartblay specifically. This work should therefore be understood as disability anthropology, work that engages with and foregrounds theoretical concepts from critical disability studies while starting from and focusing on the point of view of people with disabilities themselves (Hartblay 2020), highlighting indigenous meanings (Kasnitz 2020).

Disability anthropology departs from the point that disability comes into being through social relations, one cannot be disabled alone (Hartblay 2020). The work of disability anthropologists distinguishes itself by regarding people with disabilities as experts of their own experience, foregrounding their point of view and analyzing it by primarily engaging with disability studies theory. Hartblay (2020, 26) calls for anthropologists to claim disability anthropology as a space for critical, interdisciplinary knowledge". In addition, she encourages ethnographic reflection on the domain of disability expertise specifically. This thesis can be seen as a response to her call for claiming disability anthropology and combine the study of local lived experience of disabled people with the theoretical drive of critical disability studies to analyze "how people with disabilities mobilize power in the context of diverse cultural configurations of pervasive systems of compulsory able-bodiedness" (Hartblay 2020, 27).

Research question and aims

In this thesis I will connect the concepts of mobility, disability expertise, ableism and neoliberal self-making to understand how social mobility is established by young disabled people in a neo-liberal society. This thesis thus focusses on the experience of a group of people that experiences immobility on a daily basis: people with physical impairments that are a force for disablement and mobility limitations. By looking at the ways in which mobility is formed and contested in physical and social ways by my participants I aim to answer the following question:

How do young people with disabilities use their disability expertise to establish social mobility in a world that consists of environments based on ableism?

By answering this question, I aim to contribute to a gap in the literature on how (im)mobility is experienced and shaped by disabled people as active, knowledgeable and capable experts. I have strived to move away from the dominant approach of looking at disabled people through the lenses of stigmatization, discrimination, impoverishment, abuse, neglect, dispossessment etc. (Hartblay 2020, 27) in order to firstly, do justice to the capabilities of my participants and, secondly, allow for a better understanding of how social mobility is established by disabled people themselves when the physical and social environment is not accustomed to one's body.

Understanding the establishment of social mobility by disabled people is crucial since one should never forget that unlike other social categories that are rather fixed and often unchangeable like race, age and gender disability is a category that could enter one's life at any moment. (Kumar 2016) and has far-stretching implications for our place in society.

Contextual introduction

This research on disability and mobility was conducted in The Netherlands in collaboration with participants aged 16 to 31. According to RIVM statistics of 2016, 8 to 12 percent of inhabitants of most Dutch municipalities have a mobility-constraining disability. Since 2015, the national government has taken on an approach aimed at the self-sustainability and independency of people with disabilities which needs to be financially supported by the municipality the disabled person lives in. In practice this means that the approach to accessibility and support for people with disabilities can vary based on the place they live, often having a great impact on their daily experience of disablement. Additionally, in The Netherlands the idea of a "participation society" (participatiemaatschappij) is promoted by the prime minister. According to this idea about society, all members of society should contribute to the participation of themselves and others in society and calls on their responsibility to do so. In this manner, participating in society depends heavily on your social network, and their as well as your own motivation and ability to encourage participation. Important to note here is the fact that The Netherlands is a neo-liberal, capitalist country which makes that participation often immediately gets linked to education or work (Fritsch 2015). However, disabled people are often excluded and absent in the field of education, employment and public space (World Bank 2019; Titchkosky 2011; Hartblay 2019; Jaffe 2015).

Besides these social factors, physical and geographical components also play an important role in the mobility and social position of disabled people. Firstly, The Netherlands is a very flat country. This might not be influential to all types of disability but for those using a wheelchair the lack of hills and mountains makes it easier to move around. Secondly, in 2017 it became obligatory to make public buildings accessible to wheelchair users. In addition, The Netherlands has signed the United Nations Convention on the Rights of Persons with Disabilities back in 2016. By signing this convention, the government officially agreed to protect, support and guarantee the rights and dignity of people with a handicap of all sorts. Additionally, they declare to contribute to the elimination of the big social disadvantages of people with disabilities and to encourage and ensure their participation in the civil, political, economic, social and cultural life with equal opportunities and without discrimination. Unfortunately, after signing the convention, a research conducted by an alliance of the United Nations in December 2019 concludes that the position of disabled people in the Netherlands is insufficient. Despite of the convention, the unemployment rates and poverty among disabled people in The Netherlands have risen while access to education for disabled children has decreased (Trouw 2019). Soffer, head of Iederin[1] notes that despite all the laws, acquiring a "normal" place in society often means adapting to able-bodied for disabled people. Altogether, mobility and disability in The Netherlands is, among other things, framed by geographical aspects as well as recent changes in ideas of participation in society and a shortcoming of social and physical means to attain full inclusion.

Structure

The remainder of this thesis is organized into 5 chapters.

Chapter one outlines the process behind this ethnography. I will explain how I met the participants of this research, which qualitative research methods were used while working with them and the ethical considerations that played a role in how the collected data was handled. Additionally, the participants will introduce themselves and explain who they are and why they decided to join the research. Lastly, I will reflect on my personal role and bias as an able-bodied researcher working with disabled participants of which one is also my sister.

In chapter two I will elaborate on the various ways in which both physical and social exclusion arises for people with disabilities and shed light on the ways in which ableist norms are fuel the emergence and sustenance of exclusionary spaces. Subsequently, I will focus on how this exclusion is experienced in both physical and social ways.

Chapter three will discuss how omnipresent exclusionary spaces are an important force for the creation of spaces specifically meant for, used and often created by disabled people. By creating these disability spaces, two worlds emerge. The big world, which is the common world we all move through, and the small world, which is built specifically to accommodate disability. The small world plays a vital role in gaining and spreading disability expertise through which new ways of negotiating access and desiring disability open up.

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[1] Iederin is a Dutch network for people with a handicap or chronic illness that uses the Convention on the Rights of Persons with Disabilities (CRPD) as a guideline towards inclusion and an accessible society with equal opportunities for disabled people.

In the final chapter of this ethnography I will illustrate how the specific disability knowledge people gain in the small world is used and enacted to ultimately gain social mobility and to establish one’s place in the big world. I will do so by looking at the ways in which their gained disability knowledge informs ideas of the self in relation to neoliberal self-making and disability. The accounts of the participants will highlight how disability expertise and moving through the big and small world simultaneously helps to form paths towards these adjusted (neo-liberal) identities.

Finally, chapter five summarizes the results of this research and will present the conclusions.

Chapter 1 – Actors, Methods & Ethics

Introduction

In this interpretive qualitative study, theoretical findings of other researchers are presented in critical dialogue with the empirical data I gathered during the three months of fieldwork. The fieldwork was conducted from February 3rd until May 15th 2020 in The Netherlands in close collaboration with my participants.

In this chapter I will firstly explain how I got into contact with and selected the group of participants. Subsequently I will reflect on my own positionality and bias as an able-bodied researcher working with disabled people on the topic of disability and mobility. Furthermore, I will elaborate on the methods I used to gather empirical data in collaboration with my participants. I will also touch upon the ethical considerations that played a role in the methods I used as well as the ways in which I gathered participants and handled and secured the data their personal stories provided me with. Lastly, it is important to note that the fieldwork took place during the outbreak of Covid-19 in The Netherlands. The governmental policies that restricted movement and social contact had an enormous impact on the lives of my participants, me, the data I gathered and the research methods I used. The reflection on the ways in which this impacted doing qualitative research based on participant observation in the specific setting of this research will be woven into the description of the research process.

By providing this information I aim to give a transparent and comprehensive overview of how the findings in this research were gathered and formed through my methodological choices I made, an unforeseen pandemic, and the personal background and ideas I carry with me as a person.

In the first steps of designing this research, I came to the realization that I wanted to look specifically at how disabled people navigate the social and physical environments other able-bodied citizens move through as well. This meant that I made the decision to not locate the research in an institution or organization designed to accommodate for only or mostly people with disabilities. This implied that there was no physical space I could turn to where I knew I would find possible participants. I could not go somewhere and build a network through my physical presence. This led me to think about ways I could reach out to future participants and what kinds of people would be suitable and willing to provide insights that would ultimately help me answer the research questions.

Due to the fact that this research evolves around the question of futurity and future perspectives, I decided to aim at participants in the age of 16-30 because in The Netherlands

people of this age group are most often active in the process of defining and designing their personal future (Steinberg 2011).
As mentioned earlier, this research predominantly focusses on physical disability and (im)mobility. It thus seems logical to gather disabled people and ask them to participate, but what disability actually entails and who can and cannot be labeled as disabled is a matter of ongoing complex debate (Kasnitz 2020). This also holds true for the question of what mobility precisely is and who is mobile and who is not. Therefore, I chose to let future participants decide for themselves whether they fit the requirements and could be of value to the research. I thus stated in my initial contacts that in order to participate they had to feel like they had a disability and were faced with mobility limitations because of it.

The first participant to become part of the research was my sister Carolien, who has been the inspiration for this research and has always greatly supported it. We are enrolled in many relationships; first and foremost, we are sisters, but also employer and employee, researcher and participant. I will reflect upon this entanglement of relationships in this chapter under positionality.

To reach out to other participants, I used a snowball-based tactic and asked my sister to ask others in the same position if they would like to participate. She came up with the idea of posting an invitation to participate on the social media channels and groups she and other people with disabilities were part of. I have to acknowledge that my sisters' regular involvement in these groups and the connections she already made there were hugely beneficial for the recruitment of participants. Through the invitation that Carolien posted on her personal Instagram and in different Whatsapp groups dedicated to specific disabilities, treatments or conditions that called for young people who self-identified as disabled and mobility restricted, I managed to get in contact with Sofie, Lisa and Christel. These three young women were born without the physical impairments they face now. They thus have lived and navigated the world as able-bodied people before, which gives them the special ability reflect on the world both from an able-bodied and disability perspective.

Besides using my sisters movement in online disability groups and her related network, I also reached out to an organization called Wij Staan Op!, who focusses on the inclusion of young disabled people in society. They connected me to one of their members, Marianne, who later also agreed to participate in the research. During one of the interviews I had with her she introduced me to Yuna, another young woman who had a disability and experienced mobility restrictions and who played a smaller role in the research. Marianne and Yuna were both born with their disability and have never experienced and navigated the world as able-bodied members of society.

Carolien, Sofie, Lisa, Marianne, Christel and Yuna grew to be the amazing group of participants without whom this research could not have been carried out. To do justice to their personality, personal stories and motivation to participate they have written a short text to introduce themselves.

Lisa: I am Lieke, a positive young woman. I'm the "mom" of a lovely assistance dog, proud aunt of two sweet girls, creative, sporty, eager to learn and a little stubborn. For approximately one year now I have been depending on a wheelchair and tube feeding. The fact that I'm using a wheelchair made me want to participate in this research. Recently I had to think about my ideas for the future and I have experienced which barriers can occur for people with mobility disabilities. Those are both practical and emotional things that I did not think about before but became my daily reality. I hope to contribute to this research by sharing my ideas and experiences.

Sofie: Hey hey, I am Sofie, 17 years old. I was always a very healthy, athletic and intelligent girl. Hockey really was my passion, I was following bilingual education and had good grades. You would think everything was perfect. That was until I got an injury 2.5 years ago while playing hockey. This injury changed my life, I got CRPS. Suddenly I had become a girl with a disability and had to reconfigure everything. I learned that there is actually not that many possibilities for people with a disability. You are faced with many barriers to (simple) things and you don't receive a lot of support in that. Suddenly your world changes. In the meantime, I have found my way and have a more positive look at live again. I even graduated from high school! This took a lot of hard work and it was not easy. I really want things to become easier for people with disabilities and want us to be treated equally and have the same rights. This is why I participated in Annelies' research, to hopefully make the world a little better for people with a disability.

Carolien: My name is Carolien, I'm 25 years old but unfortunately living in the body of an 80-year old. My disabilities cause me to be pretty much unable to walk, which makes me completely wheelchair dependent. My arms make uncontrollable movements which complicates doing anything for which you would use your arms. Lastly, my stomach is paralyzed and so I cannot eat regular food but instead rely on tube feeding. This is a short summary of my disabilities who make daily life a challenge but not impossible to live! I like going outside, meeting friends and singing in my choir. Due to my low level of energy which is partly the reason why I can no longer study or work, I continue to develop and educate myself at home by watching documentaries, talking to other disabled people and sometimes helping them move further. There is a large community on Instagram where we support each other, which is very nice. Every now and then I write blogposts for a woman that runs a disability coaching organization in which I share my thoughts and experiences with others. When Annelies told me she was going to conduct this research I felt very happy. I decided to participate because I feel like young disabled people are often forgotten or diminished while they should be heard. We have many talents, passions and ambitions that are not being used right now and we are often not given the opportunity to develop them. Hopefully this research will help people to listen and hear the stories of disabled youngsters and encourage others to see our value just like it encouraged me to see my own.

Marianne: I am Marianne, I'm 30 years old and I live in Enschede together with my assistance dog, Buddy. I've studied social work and services and currently work for the municipality of Enschede as a WMO[2] consultant.

I love reading books and gaming and like to go out every now and then. I'm social, a real go-getter and have a big sense of responsibility.

I was born with cerebral paresis. This means that sometimes I have to do things differently, it does not mean that I am different. I think visibility is very important as well as realizing that people with a disability are not weird or forlorn. Just like any other person I have dreams that I aim to turn into reality. I would like to see improvements in the ways disabled people are being portrayed, that's why I joined Wij Staan Op![3]. I decided to join the research because I think it is a very interesting subject which I think about a lot and also struggle with sometimes.

Christel: Hi, I'm Christel Verbogt. I am a communication professional and follow a part-time study program on communication. In 2017 I started my own company: Christel Poweronwheels. Currently I am a blogger, a collocutor for policy makers and entrepreneurs who aim to work on accessibility and my story has been shared multiple times in the media. I am committed to creating a more realistic image of people with disabilities. Why are we not represented in movies or series? And even if we are represented, why are we portrayed as

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[2]

[3]

piteous or unhappy? Or why do these characters die or miraculously cured? My message is therefore: think in possibilities, not in limitations/disabilites; what are the possibilities?
I decided to participate in this research because I think social mobility is very important and I want to help inspire people. You never know if or when disability comes to affect your life. Personally, I came to use a wheelchair unexpectedly and it was very helpful for me to read the experiences and ideas of others because I had no idea about what things were still possible.

All of the participants identify as women, are white, Dutch, and have no immigration background or do not belong to an ethnic minority in The Netherlands. I am aware that the experience of disablement always intersects with other defining social identifications such as gender, sexual orientation, race, age, financial situation etc. It is therefore important to understand that the individual experiences of the group of young white disabled Dutch women who form the fundament of this research should be understood while keeping their social identifications in mind. With this research I do not aim to actively say something about the role of gender, race, ethnicity, sexual orientation etc. in the experience of disability. However, I am aware of the fact that these categories influence the experience of disability and I encourage further intersectional research to gain more insights into the ways disablement is shaped by them.

Research Methods

This thesis should be interpreted as the final product of an interpretative qualitative study conducted from the 3d of February until May 15th 2020. It must be understood that I have never strived to find an absolute truth, rather I have used the gathered data to describe subjective experiences which might not be universal but are valuable to our understanding of how mobility and disablement are formed and experienced by different people (Rosenburg 2012).

In order to answer the research question, I used multiple qualitative research methods including participant observation, semi-structured and open interviews, informal conversation and an analysis of online material such as social media posts, policy documents, blogs and websites. To get a better understanding of what these research methods entail I choose to follow the definitions as formulated by O'Reilly (2012). She notes that participant observation entails a combination of joining in and immersing yourself in the daily lives, environments and activities of participants for a longer period of time while maintaining a more distant, critical role which allows you to simultaneously observe the things that are

going on (O'Reilly 2012, 106). Participant observation was practiced during a municipality meeting on inclusion, walks through the hometown of participants, joining a wheelchair fit on, conversations with specialists or doctors and simply spending time together.
It must be noted here that due to the outbreak of Covid-19 during the fieldwork, participant observation became almost impossible after the 15th of March. The government of The Netherlands said visiting people who had higher risks of severe health problems due to Covid-19 should be avoided as much as possible. All of my participants fell into this category and so I chose not to visit them in person anymore for safety reasons. This means a majority of the data presented in this research was gathered through online communication. As Janghorban et al. (2014) note, Skype as an online service offers researchers the possibility to conduct interviews when there exist problems in having conventional face-to-face interviews. Following Janghorban et al.'s (2014) advice, I used Skype to encourage participants and myself to participate in the research despite of our mobility limitations due to Covid-19. In cases where the participant was not familiar with the use of Skype, I went along with their preferred means of communication since using Skype nonetheless could affect the nature of the interview (Deakin & Wakefield, 2013 in Joanghorban et al., 2014). This meant that some interviews took place using Whatsapp videocalls, Whatsapp messenges or regular phone calls. Whereas face-to-face time with most participants became highly problematic, the time I spent with my sister increased. This was due to our own wishes to see each other as well as the effects of a decline in access to healthcare and therefore the emergence of a bigger dependency on me as a caregiver. In this manner, participant observation always kept being one of the used research methods throughout the time of fieldwork.

The interviews I had could be labeled as semi-structured interviews. I either met the participants at home, at a location of their choice or made appointments to meet on Skype and made a topic-list in advance. However, questions were never fully formulated beforehand, and the conversations were often altered based on the answers and input of the participants. Sometimes these interviews were recorded and transcribed with consent of the participants, other times I wrote down notes during the interview. This method of taking fieldnotes was used during the entire period of fieldwork in order to capture experiences and observations directly when they happened (O'Reilly 2012, 101). These notes also contained my personal feelings and considerations which enabled me to be more reflexive and recognize how my presence and mood influenced the data during the process of analysis (O'Reilly 2012, 104).

Lastly, analyzing social media content that was posted by my participants became an unforeseen but very useful method for data gathering. I knew of the existence of social media groups and personal online connections linked to disability, which had also played an important role during participant recruitment, and so I decided to steer the research in that direction. As Postill and Pink (2012) note, social media practices are often part of how participants navigate their social and material worlds. I adopted their vision since it resonated perfectly with my research question. This was done by integrating the data my participants posted online into our conversations and moments of participant observation which also illustrates how data triangulation was accounted for.

The data presented in this thesis was gained through a mixture of these different research methods. Before they were used in this document, they have been thoroughly analyzed, coded and revisited.

Reflection on personal positionality

My position as a researcher on the topic of disability and mobility could impossibly be completely neutral. First of all, I am an able-bodied woman myself, therefore it is impossible for me to fully experience what life is like as a disabled person. Oftentimes disability simulation is used in an attempt to overcome this difference, but I consciously chose not to do that. As Young (2014 in Parent 2016) says: "*disability simulation fails to capture the nuance and complexity of living in a disabled body. And it certainly fails to give a deep understanding of systemic discrimination and abuse faced by disabled people*". Instead, I regarded my able-bodiedness as a useful tool to investigate the links between the two worlds that my participants described. One of the participants explicitly acknowledged this value by stating that she realized that although she could teach me a lot about the world of disability, there was also a possibility in it for her to learn more about the so-called normal world.

In addition to me being an able-bodied researcher, my interest in disability was sparked by personal experience. For over 10 years I have seen my sister handle different levels of disablement which had a substantial impact on her life and place in society. According to Kasnitz (2020, 19), being a nondisabled family member gives you "disability proximity" or a larger societal "disability exposure" that allows for a "cross-impairment synergy (Kasnitz 2020, 19). What Kasnitz (2020) means to say by this is that when people have significant exposure to disability, they can become adept at recognizing disability expertise and assisting in a manner that makes disability background while it foregrounds other activities (Kasnitz 2020, 19). This was also recognized by my participants who believed that because of my experience with disability they felt like I was less judgmental, held less prejudices and would be more capable of understanding them than most other able-bodied people.

As a researcher this disability exposure and cross-impairment synergy helped me immensely to gain access into the world of disability and build rapport as well as recognizing meaningful acts of disability expertise.

Lastly, although I worked with my sister as one of my participants, I am not aware of any conflicting interests that could have influenced the outcomes I present in this thesis. Helping my sister navigate the physical and medical world and discussing this was already a part of our relationship before this research started. This is also part of the reason why she asked me to be her official assistant that would be paid a small amount of money by the municipality. As a consequence, we were already used to collaborating in a more formal way while also remaining our bond as sisters. Even though this formally made me Caroliens' employee, there were no changes in the things I assisted her with since I already did that as being her sister. Altogether I state that my view could not possibly be entirely objective, but, to my awareness, there were no conflicting interests that could potentially harm this research.

Ethical considerations

During the research I took ethics into careful consideration. This meant that the participant who was 16 and thereby a minor under Dutch law, discussed her participation with her parents and together they signed a paper that explained the goal of the research, the research methods as well as her rights as a participant. Additionally, I told all the participants about my role as a researcher and what the study I was conducting was about. They all explicitly agreed to take part and were aware of the fact that they could stop our collaboration at any moment. The data I gathered from interviews or social media was either stored in a secured, private, digital environment or in my paper notebook. The participants were informed about any recordings during interviews and those who wished so, have been given pseudonyms in order to stay anonymous. A short comprehensive summary of the research was handed to them in Dutch. The full document was also provided to them.

Chapter 2 – Living on the edge

On disability and (im)mobility

Introduction

According to Dalakoglou (2012) mobility is one of the most important aspects in defining the human condition in our current times. However, mobility is not experienced in the same ways by everyone. Although disability exists around the globe and has always been part of humanity, disabled people continue to face physical and social barriers that limit their mobility and blocks them from fully being included in society (World Bank 2019, WHO 2011, Titchkosky 2011, Kumar 2016, Gofmann 1963; Hartblay 2020; Kasnitz 2020). The barriers and obstacles that people with disabilities encounter that limit mobility and participation in society have been studied elaborately in the field of disability research (Titchkosky 2011; Hartblay 2019; Goggin 2016; Jaffe 2015). The scope of disability has also added much value to the study of mobility as a whole (Jaffe 2015). It is however not enough to let the experienced (im)mobility by disabled people mainly inform the study of mobility. To understand how social mobility is shaped by people with disabilities, we must also look at how mobility informs the experience of disablement. If we do not critically examine how mobility and disability interact in diverse ways, we miss out on what it means to experience disablement and how this experience relates to the ways in which disabled people create social mobility for themselves.

As pointed out by numerous researchers, ableism turns out to be deeply rooted in society and forms a source of immobility and exclusion for disabled people (Titchkosky 2011). A continuous confrontation with countless physical and social barriers decreases their ability to participate physically and socially (Jaffe 2015). Examples hereof that were mentioned by my participants are stairs, narrow doors, existing ideas about disabled people being less intelligent, athletic or outgoing. In this chapter I will look at how ableism works to create and sustain physical and social barriers and how this leads to experiences of exclusion in the lives of young disabled people. I will argue that the ways in which ableism works in the creation and limitation of mobility is a complex multi-directional process. It is essential to understand this complex process since it opens up the way to see where and how disabled people find places to shape a future for themselves.

Ableism as an obstacle to mobility

> *The second day after I officially started my fieldwork, I attended a municipality gathering that focused on the inclusion of people with disabilities into society. The goal was formulated as "letting people with a handicap live as independent and autonomous as possible" on the website. The municipality claimed to be a "fore runner municipality" on the matter of inclusion, so I felt excited and expected quite something. I send one of the public speakers on this event, Christel, a message on Instagram to reserve a seat. My sister, Carolien decided to come with me out of curiosity. After I climbed the chairs at the majestic front door of the city hall, and my sister used the elevator in the back, we both sat down in the old city hall. We listened to various people speaking about segregation, inclusion and accessibility. In the entire room there were just two people with directly visible disabilities. My sister and Christel. Christel was invited to help think about what the event should look like, and to speak about her experiences as a wheelchair user in the city and share her ideas on inclusion. She stated that she started to experience various barriers that limit her participation in society after she had to start using a wheelchair. She described the existence of two worlds that do not understand each other as a source for the barriers she encounters. Everyone listened carefully and agreed on the fact that accessibility has to be improved and the inclusion of people with disabilities accommodated. At the end, the manifest "everyone participates", based on the VN convention on the Rights of Persons with Disabilities was officially signed. After the paper was signed the two men who had signed it showed it to the public and shook hands. Some journalists came forward to take pictures of this scene. We then were invited to stay for drinks and talk with each other. As soon as we entered the room in which the drinks were served, my sister and I looked at each other and laughed. After an entire meeting about accessibility and inclusion, the room was filled with standing tables. Nobody seemed to notice, and everybody gathered around the tables and started chatting. Carolien and Christel placed themselves on the side of the room. The conversations at the tables were literally taking place over their heads. My sister told me she did not feel like she could participate in these conversations due to the standing tables. After talking to Christel, she felt tired and so we left, after having to ask for the key for the elevator which could not be accessed independently or autonomously as the meeting aimed for.*

According to Titchkosky (2011) the barriers and obstacles like Christel described and my sister experienced that afternoon, emerge from able-bodied norms based on which we design and build our physical as well as social world (Titchkosky 2011). We design and build our social and physical environment in a way that facilitates and prioritizes accessibility for able-bodied people. When one does not fit the able-bodied norm, they are faced with many obstacles that ultimately renders spaces less accessible or even inaccessible. One of the things that keeps this inaccessibility in place is the idea that the barriers disabled people face are natural, reasonable and justifiable (Titchkosky 2011, 4). The continuous creation and endurance of these justified barriers, and therefore the exclusion of disabled people, has everything to do with ableism. Ableism is the devaluing and discrimination of disabled people through practices, perspectives, behavior, and assumptions that recognize and prioritize physical (and sensory and cognitive) norms that fail to accommodate for difference (Saltes 2018, 82).

The situation at the municipality meeting shows how the design of our physical world remains based on able-bodied norms (Titchkosky 2011). These norms appear to be so persistent that even when we do actively and consciously think of disability inclusion, we are still not able to take those barriers away and actually continue to create them. On an event dedicated to inclusion, it apparently still seems logical to put standing tables in an area where further conversation about inclusion is encouraged. The placement of this physical barrier let Christel and Carolien to move to the sides and not take part in the conversations held at the tables, thus also partly excluding them socially. This situation is an example of the larger processes scholars described, they note how the ways in which we move and where we move influence how we perceive ourselves and how other perceive us, it defines to which social groups we belong and when or where we are excluded. This illustrates Titchkosky's (2011) argument that physical and social mobility are tightly interlinked and should not be seen as separate because they are both vital to being mobile. In this particular case the physical design of the environment does not just block physical movement for Christel and Carolien, but also their mobility in social conversations and their participation in the group. Additionally, the goal of the meeting was to enable people with disabilities to live as autonomously and independently as possible, but Carolien still had to ask for a key in order to be able to leave the building. This event illustrated explicitly that ableism is so deeply wired into our system and forms such a persistent norm that it often remains in place, even when we actively try to avoid it.

Barriers created through ableism were experienced by all of the participants in this research. I choose to separate them into two categories: barriers that don't allow to physically reach or move through a certain place, and barriers who don't allow to socially take part in society in a way that is equal to able-bodied counterparts. Both types of barriers limit the physical and social mobility of people with disabilities, they are thus inherently interlinked. Physical barriers were often the most visible obstacles to be encountered to me and the participants who were facing them. The situation I described above is a good example of physical barriers but there were many more to be encountered during my research. From stairs, high sidewalks, narrow entrance doors, little space between tables in cafes, inaccessible toilets to high placed desks and narrow shops.

> *One time me and my sister wanted to cross a bridge to the city center that was being renovated and was temporarily inaccessible due to the construction work. Alternative transportation for less-mobile people was offered but upon calling the designated taxis, it turned out they could not transport non-foldable wheelchairs. Carolien stepped out of her wheelchair, climbed the chairs with difficulty and waited for me to find a random passenger to help me carry her heavy wheelchair up the stairs as well. I asked her how she normally crosses the bridge by herself. She replied: "This happens regularly, I am used to it and just take another route (one that takes at least 25 minutes extra) but when you are there it is different. With you I only need one other person and you can ask for it, I find it hard to bother others and don't want to be a burden".*

Even when the municipality had thought of disabled people who wanted to cross the bridge, you could still only use the taxi-service if you could walk and use a foldable mobility aid. This situation again proves how deeply rooted ableism is and the effect it has on the design of our physical world and the physical barriers that emerge from ableism. However, it also highlights social barriers. The fact that Carolien feels different when crossing the bridge with an able-bodied person shows how ableism is sometimes also part of the behavior, feelings and thoughts of disabled people. She feels like she can better conquer the barriers when she is accompanied by an able-bodied person and actively acts upon that idea. She alters her behavior based on the presence of an able-bodied peer and this presence influences her ideas about what she can and cannot do. The same behavior was described by Marianne and Sofie who felt like they were more capable of doing things and conquering barriers when they were with an able-bodied friend or family member. Their experiences support Cresswell's (2010) statement that mobility is a complex entanglement of getting from one place to another, giving meaning to this movement and the experienced and embodied practice of movement. To go from A to B for the participants was linked to the ways in which they gave meaning to their movement, being accompanied by an able-bodied peer changed the meaning of the movement, it made it easier and took away the sense of being a burden, thereby changing the experience and embodied practice of mobility.

The examples and barriers above show how impingent ableism is on the emergence and continuity of physical barriers and the social effects hereof. Not only do barriers get naturalized and justified by institutions and able-bodied people, they also get naturalized by disabled people themselves. They feel like it is natural that they are able to do more together with able-bodied peers. In this way ableism does not only inform the creation and continuation of physical barriers and their social consequences, it also informs the behavior and movement of disabled people themselves. How deeply our ableist environment influences behavior and movement of disabled people became clear in one of the conversations I had with my sister on her couch. Carolien explained to me how widespread these barriers are and how impingent they are for her mobility and place in society. She told me that she loves the idea of going outside and regularly looks forward to doing so. However, she often decides to stay inside nonetheless because outside is where she is confronted with being different. Because this difference is poorly accommodated, it almost feels as if she doesn't belong there. This connects to Yuval-Davis' notion of belonging; an act of self-identification or identification by others through a construction of hegemonic power relations (Yuval-Davis 2006, 199). The able-bodied norms that ultimately lead to social and physical barriers are so omnipresent that it leads Carolien to self-identify as being different, therefore not belonging because the hegemonic ableist power relations that shape these barriers do not accommodate to her. As a result she either plans her trip thoroughly making sure her destination is actually reachable or prefers to take an able-bodied friend or family member with her. This tactic was also used by Sofie, Marianne and Lisa. They often called a certain location to ask if they could actually go inside with their wheelchairs, continuously checked the road when they were in a street they didn't went to before or made sure they had an able-bodied friend or family member with them to conquer barriers with. Carolien even stated that to go outside she needs "*an extra pair of eyes and hands*". Marianne felt like she could best face and conquer barriers when she went out with her best able-bodied friend. She saw this person as incredibly important to her mobility and participation. Titchkosky (2011) says that access is largely shaped by the relationship between our bodies, space and others. I would argue that the tactic of bringing an able-bodied peer with them proves successful because in this manner, disabled people can alter their socio-spatial relationships and negotiate the hegemonic power relations, allowing them to alter the level of access.

In short, ableism is so deeply rooted in our social and physical environments, behavior and thoughts that it is always part of the way in which we experience and create (im)mobility, both for disabled as well as able-bodied people. I would argue that ableism is rooted so deeply in the world around us that in order to conquer ableist obstacles, disabled people often rely on able-bodied people because through the system of ableism, they are (often literally) the ones who can open the doors to new possibilities of relation to socio-spatial environments. By letting this power remain in the hands of able-bodied people, we keep enacting and reinforcing the ableism that formed the barriers that we try to conquer and we all naturalize and justify the fact that these barriers exist in this way.

Social immobility

In the former paragraph I mainly focused on how physical barriers illustrate the connectedness of immobility, mobility and disablement to the able-bodied norm we all seem to have and act upon. Although I already hinted to the existence and effect of social barriers I will dive deeper into that matter in this part of the thesis. In this paragraph I will explain how physical barriers inform the existence of social barriers and how this has implications for the social role we assign to disabled people and the roles disabled people assign to themselves.

According to Saltes (2018, 82), physical access is always interlinked with the social organization of participation and belonging. Because we design big parts of our social and physical world based on able-bodied norms, we create exclusionary spaces for people who do not fit that norm (Titchkosky 2011, Saltes 2018, Hartblay 2019). Titchkosky (2011) argues that inaccessible spaces become sites of exclusion because they actively show who belongs somewhere and who does not. Jaffe (2016) takes this idea further by stating that spatial mobility shapes social life. These implications on social life were often experienced as more of a problem and more discriminative than physical barriers by my participants. *"Inaccessibility of buildings feels less discriminatory than having to perform better at school", Sofie says.* Lisa described her struggle with social barriers as the experience of *"not* *fully being recognized”.* Marianne argued that physical barriers were not her primary concern because she learned to avoid them and is now used to move around them. Instead it was the social implications of those barriers that ultimately made her feel different and left out. It is often assumed that accessibility, and thus enabling physical mobility, will lead to social mobility and ultimately inclusion, but the experiences of the participants suggest that the connection between physical and social mobility is not that linear.

To get a better understanding of the complex ways in which spatial mobility shapes social life we have to look at how the body interacts with socio-spatial environments and social attitudes (Saltes 2018, 82). In the case of my participants, their bodies often could not access socio-spatial environments as I explained in the former paragraph. This inaccessibility leads to exclusion both in bodily presence and social participation. According to Titchkosky (2011) the barriers that lead to this exclusion often get naturalized and justified, and I have noted that participants themselves often naturalized and justified these barriers too. I would like to add to that argument by stating that not only barriers get naturalized but so does the absence of disabled people. According to Sofie, people started to perceive her absence as “logical” after she did not attend classes at school for some time due to physical barriers. Marianne and Yuna told me that whenever they told someone about an activity they did that was not perceived as something disabled people could take part in, sky-diving in this case, able-bodied people always asked the same question: *“But, HOW?!”.* These examples are expressions of the ways in which we have naturalized the absence of disabled bodies so strongly, that we come to see their absence as logic and often cannot practically imagine their participation anymore. Christel noted that she actively had to remind people to *“think in possibilities*” because they automatically assumed things were often impossible for people with disabilities. The disabled bodies of my participants were simply perceived to be incapable of belonging and participating in certain places and activities.

What is interesting here is that the participants’ stories suggest that it is not just the able-bodied people within society who naturalize the absence and perceived incapability for participation of disabled people, disabled people also naturalize this themselves. Marianne told me that because the focus in accustomed schools, hospitals, social settings and the like were always on what she could not do, she became to believe this. In various ways, wherever she goes, there is always a focus on what she cannot do and where she cannot go.

"They see your disability and expect: there's nothing in there, nothing will ever come out of it and it will never be something. Hide them (the disabled), so I don't have to look at them."
This message is given continuously to people with disabilities through our physical and social environment, and the accounts of my participants show they often also grow to believe in that message.

This constant reminder of not belonging in the social and physical environments able-bodied people move through and the constant denial of access that creates exclusion, ultimately leads to having trouble navigating social spaces. This connects to what is stressed by multiple researchers (Jaffe 2016, Titchkosky 2011, Saltes 2018, Cresswell 2010): spatial mobility shapes social life. I would like to illustrate this by describing one of the moments I spent with Marianne.

> *It was the first time I met Marianne and we were walking through the streets of her city towards her home after she came to pick me up from the train station. She was using her electric wheelchair, her assistance dog and I were walking next to her. One of the first things we talked about was how difficult it was to adjust the speed of an electric wheelchair to a general walking speed. "Those things either go too fast or too slow". Since it was the first time I met her, I did not want to put all the attention straight to her disability or mobility aid, so I started to chat about other things to make us both feel more comfortable. I made comments on the places we passed by, told her my impressions of her city, asked for how long she had lived there, why she had moved there and connected her answers to my own experiences. I tried to build a connection this way, but I noticed how Marianne did not respond that much. I could not figure out why until she stopped me in the middle of a big square. We were surrounded by cafes that looked very cozy and welcoming to me. "Look", Marianne said, "I am not that good at small talk and I do not really like it". I asked her why. She explained that she found it hard to engage in small talk because it was based on daily life experiences, but her experience of daily life was completely different to the one of an able-bodied person like me. She looked at the cafes and said that most of them were physically inaccessible to her, but that even if they would be accessible, she would have no clue how to behave and talk to the people inside.*

This was not the first time in which I felt the small talk was not going as smooth as I was used to. In fact, whenever I tried to chat a bit during the first contacts with my participants, they quickly moved the conversation towards deep topics and explaining their personal stories about their disability. It was only after Marianne's explanation that I understood why this happened. The spaces and environments in which my daily life took place, and which formed the foundation for my small talk, were the spaces they did not belong or had access to. Due to a lack of access, they had trouble navigating these spaces, and thus they also had trouble engaging in conversations about them. Jaffe (2015) mentions that mobility is crucial to the forming of our self- and societally perceived identity and thereby shapes social life. In accordance, Salazar (2012) and Cresswell (2010) note how movement becomes entrenched with meaning. Our spatial mobility shaped our social lives, but because our spatial mobility was so differentiated, so were our social lives and therefore it was hard to interpret the meaning in compatible ways through small talk about daily activities that were linked to our physical mobility. Daily life simply was not the same for us and therefore we navigated social spaces and interactions differently. Furthermore, by not actively acknowledging their disability in our conversation, I also did not verbally accommodate for bodily difference. I wanted to get to know them but used an ableist ways of doing so, and therefore primarily gave room to get to know the person they were outside of their disability, thereby neglecting an important part of them.

While looking at the ways in which spatial mobility shapes social life (Jaffe 2016, Saltes 2018, Titchkosky 2011) I also looked at how the body interacts with social attitudes (Saltes 2018) around disability. One of the social attitudes towards people with disabilities is that "their way of doing things is disruptive to the "normal" speed, flow or circulation of people, commodities and capital because they "waste" more time and space than they should, maybe reducing profits" (Hansen and Philo 2009, in Saltes 2018). Although this argument has a very economic, capitalistic undertone, which I will dive into in chapter four, it also applies surprisingly well to the ways in which my participants described their social relationships. All the participants questioned their social "value". Lisa and Sofie stated that they often felt like always being the "*yes, but….*" in social relationships and they often felt like a burden to others when they had to slow down because of them. I had many conversations with my sister who actively questioned whether she could still be of "value" to others when she was always "taking". She felt like because of her disability she was always taking up too much time, effort and space from others while she felt incapable of giving something back.
Marianne said: "*I can imagine very well that a lot of people with disabilities think they are a burden to society. They cost tons of money because they get financial support, they just sit in*

their.. they need expensive care. When you hear this all the time in the media, how are you going to protect yourself from that?... They talk constantly about what we need, never about what we have to give" Later, while talking about her best able-bodied friend, Marianne mentioned that they had talked regularly about what her friend is actually getting out of their friendship. Yuna, Marianne, Carolien, Sofie, Lisa and Christel all stated in different ways that their social position as disabled people caused relationships to grow unequally, which made them actively question or sometimes even diminish their social value. Oftentimes, they were partly dependent on their friends' or families' help, therefore they felt less freedom to express their discontent towards them because they were afraid of losing the help. Additionally, because the world is full of physical barriers, they are often unable to reach a friends' house independently. This often results in friends visiting them, which gave my participants the feeling that growing a friendship in this manner was inherently unequal. A friend mostly had to visit them, which took out a lot of spontaneity in the relationship and made it largely impossible to physically be there for their friends whenever they needed support.

Although social attitudes towards people with disabilities made my participants question their social value, they were also not afraid to contest these attitudes themselves. As Titchkosky (2011) notes, access is also shaped by how individuals orient themselves within social spaces. Even though they thus sometimes limited their social mobility and questioned their value based on the perceptions others had of them, they also actively questioned those perceptions. As Saltes (2018, 82) notes: "*space is contingent, active, produced and reproduced and exclusionary spaces can therefore be challenged through embodied practices of mobility*". This negotiation of social space and access is often done through a specific kind of disability expertise; the particular knowledge that disabled people develop and enact about unorthodox configurations between selves, bodies and the designed world (Hartblay 2020). How disability expertise is formed and enacted in social space will be further elaborated on in chapter four. In this case, I look at the designed world not in a physical way, but in a socially designed way.

The negotiation of social space through disability knowledge was also performed by my participants; they used their body in social spaces to contest social attitudes towards disability in order to negotiate access and mobility in society. Contesting these social attitudes is crucial to creating access and therefore opening doors towards social mobility. To do so they used a kind of relational repair strategy (Hartblay 2020), when others or they themselves reacted to their bodies with surprise, pity or uncertainty. Lisa said that she could no longer get social recognition through her professional achievements in her study after she had to quit due to her disability. In this way her body was confronting her with uncertainty since her future career and occupation came to a standstill. She started to use her body differently and now gets to feel of achievement and social recognition by training her assistance dog. When she feels like people underestimate her capabilities, she shows how she is capable of training her dog and that he listens to her. In this way she contests the assumptions people have of her when they see her move around in her wheelchair, but with the same action she also contests the uncertainty about how to feel achievement from within herself. Training her assistance dog, showing it off and receiving praise and recognition of other because of it makes her feel like she achieved something. Marianne uses the same technique but solely to contest others' social ideas on disabled bodies. Carolien does not have an assistance dog, but she too uses her body to contest social ideas about disability and repair relationships. To make sure people do not underestimate her she makes sure to dress nicely and put on make-up in order to "*look less handicapped*". It is important to realize this is not an easy task for her since she does not have full control over her arm-movements. This makes putting on mascara and eyeshadow quite challenging but the social reward of both proving to herself she can do that and the fact it helps to change the way people look at her makes it worth it. Christel presented and employed herself as a public speaker besides being politically active and thereby uses her voice to push boundaries, establish her career and show people what she is capable of. She was also not afraid to tell people about the many misconceptions they have of disabled people and show them they are often not true by telling her story and putting her body in spaces you normally do not see a lot of disabled bodies such as a university, political party or city hall.

By doing these things, my participants challenged where they belong and what they are capable of both for others and themselves. These actions function as a repairing mechanism to fix the relationships they have with others and themselves when they get too influenced by common social ideas on disability. By repairing these relationships through their bodily actions, they are creating ways to navigate and move through social spaces.

All of the examples in this paragraph illustrate how physical access in always interlinked with the social organization of participation and belonging (Saltes 2018, 82). The participants' accounts of their social relationships and position illustrate how their feelings of having access to society are not just about ramps or elevators. It is not just physical access that influences participation and belonging. Social ideas about participation and belonging also shape physical access in important ways. The construction of physical sites, ideas about which bodies belong where and what they are capable of are not just experienced in a passive way. In fact, the relationship between bodies and social space is contested through what Saltes (2018) calls embodied practices of mobility informed by disability expertise (Hartblay 2020). Although disabled people experience a lot of social immobility due to differentiated access, mobility and experiences with daily life that constantly pushes them out of belonging in "normal" spaces, these social positions are also actively contested and opposed through disability expertise. For people with disabilities, to navigate through social spaces thus entails a combination of internalizing, contesting and embodying the unequal social roles our physical environment and social attitudes establish.

Chapter 3 – Moving through two worlds

On belonging, disability expertise and mobility

Introduction

As explained in the previous chapter, most social and physical environments we move through and live in are based on ableist norms (Saltes 2018, Titchkosky 2011) Our common world, which is thus based on ableism, is what my participants referred to as "the normal world" or "the big world". Because I do not want to label this world as normal, thereby falsely implying that other worlds are not, I choose to use the term big world when referring to spaces consciously or unconsciously based on ableist norms. It is through these widespread ableist norms and their widespread effects that spaces become inaccessible and thus exclusionary for people with disabilities (Saltes 2018, Titchkosky 2011). Saltes (2018, 82) argues that physical access is always interlinked with the social organization of participation and belonging. Belonging, according to Yuval-Davis (2006) is a complex configuration of social locations such as age, gender and disability, identification and emotional attachment to a group or place. As explained in the former chapter, the social location of disability that limits movement and thereby limits possible identifications, making disabled people attach differently to groups or places, fostering a feeling that they do not belong there. Similar to ideas of where disabled people do not belong or what they cannot do which I highlighted in the previous chapter, socially ideas about where people with disabilities do belong and can participate exist as well. In response to the widespread exclusion of disabled people in the big world, another world emerges: the small world. In this chapter I will elaborate on what the small world is more specifically and how different spaces in the small world contribute to the disability expertise, sense of belonging and mobility of disabled people.

The small world: bringing place and disabled people together

The small world consist of spaces that are designed to accomodate for disability; bringing disabled people, mobility and place together. According to Saltes (2018) bringing disabled people, place and mobility together shapes a feeling of belonging. I think this argument often holds true but, as I will show, disabled people do not always feel they belong in places specifically designed for them, oftentimes they actively question and resist them. Creating a feeling of belonging is thus more complex than Saltes (2018) describes. Bringing disabled people, place and mobility together does create feelings of belonging but the same process can also strongly evoke feelings of being left out. Goggin (2016) points to the fact that disabled people still face socio-spatial exclusion by often living in specialized care settings. He notes that this structural exclusionary placement of disabled people is an important factor in understanding current configurations of mobilities. I would therefore like to add to Saltes (2018) statement that feelings of belonging are created not just when disability, mobility and place meet, but when these environments also contain a lot of space for disabled persons' agency. How this works was clearly demonstrated during a municipality meeting dedicated to the inclusion of people with disabilities that I attended the 10th of February in Bergen op Zoom.

During this meeting the woman leading the discussion articulated that segregation is often being framed as a special resource for disabled people, these special resources are presented as something of which we can be proud. By special resources the woman referred to spaces where mobility and place were brought together for disabled people, spaces where they are thus meant to belong. Examples hereof are special schools, special housing units, institutions that exclusively focus on disability, sports clubs designated to wheelchair users etc. The labeling of these segregating places as special resources, makes us blind for the fact that it still produces segregation and thus further complicates the goal of inclusion. The alderman confirmed this and said: *"I recognize how exclusion arises from good intentions."*
Another occasion in which it became clear to me that the our ableist society fosters a need to create spaces where disabled people belong by bringing disabled people, mobility and place together was during a conversation I had with the driver of a special taxi-service while driving to my sisters' house. I asked the driver where she had been that specific day with the taxi. It was a normal day, she replied, and the list of where she had been consisted solely out of institutions, hospitals, medical clinics and wheelchair accommodating sports clubs. She also knew exactly which sports could be practiced with a wheelchair and where those special sports clubs were located. Although the taxi could be called and bring you to any destination of choice (within 25 km from a persons' home), it was primarily used to reach places linked to medical care, housing reserved for disabled people or wheelchair sports clubs. Even though these spaces are designed for disabled people and aim to facilitate their mobility, they do not necessarily provide social mobility in the big world. As stated before, spatial mobility is often linked with social ideas of belonging and shapes social life (Saltes 2018). In addition, Jaffe (2015) notes that mobility is crucial to the forming of our self- and societally perceived identity. This comes together in Cresswell's (2010) statement: "*some move in such a way that others get fixed in place*" (Cresswell 2010, 21). In other words, the places we move through and the ways in which we move influence how we think about ourselves and how others think about us, in this manner our mobility comes to carry social and political meaning and has to

power to either let us move freely or pin us down. This explains why my participants often regarded these physical manifestations of the small world negatively. My participants explained that by moving through these places, they were pushed further outside of the big world and further into the small world. Additionally, moving through the physical part of the small world was also believed to have a negative impact on how able-bodied members of society look at disabled people. I will now illustrate this with some of the stories of my participants.

After the municipality suggested my sister to go and live in a special housing unit in order to be able to receive what the municipality thought was a sufficient amount of help and care she got very angry and frustrated. She called me and said: *"I feel like the municipality is pushing me into the small world, and I'm not ready."* After I pointed to the benefits of moving to a wheelchair-accustomed house with 24/7 care she replied: *"Do you know what people will think if they ask me where I live, and I have to name that facility? They will think I'm crazy and incapable of taking care of myself."*
Marianne stated that she considered herself to be very lucky because she had attended a "normal" elementary school. According to Marianne, people do not learn how to behave in the big world by moving through special schools and receiving special education since there is always someone ready to help or understand you, and everything is accommodated to your non-normative needs. After having attended a normal elementary school, she had to go to a special high school because the normal one did not have an elevator. On her new school she noticed that suddenly everything evolved around her disability and that the education was given at a lower speed. She even explained how it reinforced the idea that disabled people cannot do much within herself. Since she entered the world of special education at the age of 11, which she stated as an important period for the forming of her identity, she felt like she had to *"fight not to let my disability become a part of my identity"*. She also notes that she feels being pushed into the small world. However, she now feels most comfortable there, leading to a possibility of clashes in the big world because she would prioritize the interests of the small world and the people who move through it.
Sofie refused to move through the material side of the small world. She did not want to go to a rehabilitation center to get treatment. Instead, she wanted to go to university and *"stay in my own environment",* which was located in the big world.
Christel stated that she felt that after she had to go to a special school, she lost friends and ended up standing *"on the sidelines of society"*.

Carolien expressed her feelings about the experiences with the municipality on matters that had to do with her disability and said: *"Everything with the municipality is defining my future. It feels as if I'm standing on a crossroad and if I go there (the material small world) there is no easy way back."*

These places where disabled people, mobility and place were brought together (Saltes 2018) by institutions, were thus often seen as having a negative impact on social mobility in the big world, ultimately reinforcing the idea of not belonging there. By stating this I do not mean to say that these places are terrible in every aspect, according to Marianne they also provide opportunities to interact with other disabled people and find an incomparable level of understanding. However, they also powerfully illustrates how movement impacts ideas about identity (Jaffe 2015), their often-forced movement through the physical manifestations of the small world changed the ways in which they regarded themselves and how others perceived them. In a way, it fostered a certain disablement that was not linked to the state of their physical impairments but was based on the places they move through. Being pushed into these environments of the small world also largely meant being pushed further out of the big world.

Concluding, I partially agree with Saltes (2018) argument that bringing disabled people, place and mobility together forms a sense of belonging and will dive into that in the next paragraph. I would like to highlight here that bringing disabled people, place and mobility together in a forced, non-grassroot manner can also be highly productive in emphasizing and fortifying exclusion, segregation and senses of not belonging in the big world. Actively designing segregated places and forcing disabled people to move through them is highlighting the political power of mobility. The politics of mobility involve a production and distribution and reproduction of relation of power. The segregation of people by guiding them into the physical manifestations of the small world is both a product of exclusionary power relations in the big world as well as it reproduces and reinforces these relations.

Subsequently, the segregated and institutionalized accommodation for disability leads to friction on the level of identity. As Halder (2017, 7) notes strikingly: "*identity and dignity may be compromised as lowered expectations and a lack of support and understanding limit possibilities*". Luckily, people with disabilities possess a unique knowledge that can help them going against these conventional configurations about identity, their disabled bodies and the designed world (Hartblay 2020). How this is done and how this is crucial to feelings of belonging is what I will further elaborate on in the next paragraph.

A whole world of spoonies: grassroot environments & disability expertise

The findings above evolve around the physical and material manifestations of the small world which were often joined or moved through involuntarily by my participants and were seen as limiting to social mobility in the big world. However, there are a multitude of other spaces which are also part of the small world. These spaces often do not have a physical or material place but can largely, though not exclusively, be found online. Hannelore, one of the friends my sister made in the online small world said enthusiastically: *"There is this whole world of spoonies[4] out there online, of which you did not even know it existed!"*. It is incredibly important to realize here that these spaces distinguish themselves from the material parts of the small world by the fact that here, disabled people bring disability, mobility and place together themselves. These spaces are not designed for them, they are designed by them.

In this paragraph I will explain how these environments are created and sustained through disability expertise (Hartblay 2020). Hartblay (2020) argues that disability expertise is the specific knowledge that people with disabilities develop and enact about unconventional forms of agency, cultural norms, and relationships between identity, the body and designed worlds. It is important to understand the role of disability expertise in creating and sustaining these environments since, as I will argue, this specific expertise and the movement through these environments are highly influential to the social mobility and sense of belonging of people with disabilities.

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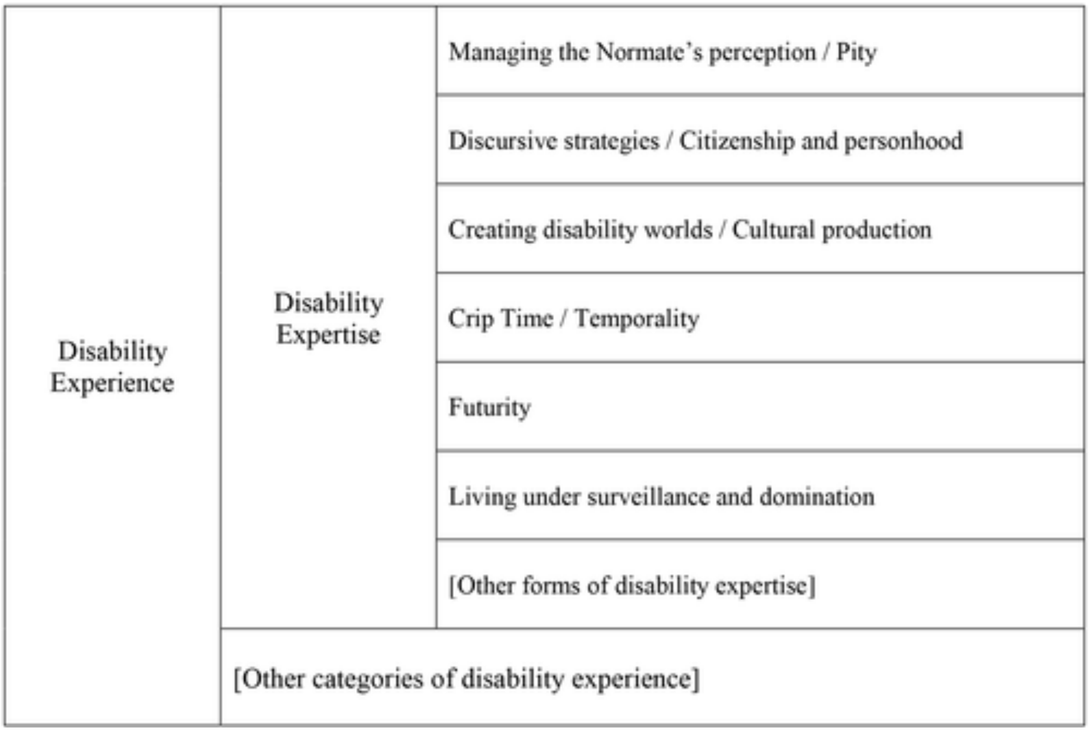
[4] Spoonies is a term used by people with disabilities or people with a chronic illness to adress people who fall into this category. A spoonie is someone who has to think critically about where they spend their energy on because they have less energy than most other people.

Firstly, it is important to understand that there is a multitude of kinds of disability expertise that can be studied (see fig. 1).



Disability Experience	Disability Expertise	Managing the Normate's perception / Pity
		Discursive strategies / Citizenship and personhood
		Creating disability worlds / Cultural production
		Crip Time / Temporality
		Futurity
		Living under surveillance and domination
		[Other forms of disability expertise]
	[Other categories of disability experience]	

Figure 1. Source: Hartblay (2020, 31)

As the figure shows, creating disability worlds is a specific kind of disability expertise that relies on disability experiences. This also came forward during one of the interviews I conducted. I asked my participant what it took to become part of the small world. She answered: *"I would say that if you became disabled, you could buy a house there and when you are close to someone with a disability, like your sister in your case, than I would say you can rent a house, do you understand the difference? You can go your … you can be part of it but you are not a permanent resident" Me: More like I would get a residence permit? Marianne: Yes, something like that, I think you are already part of it without realizing it. I think you stand inside the small world with a toe already, but with both legs, no that won't be possible unless you come to develop a disability or get one".*

This quote shows how the experience of disablement or the disability proximity of nondisabled people is crucial to having different levels of access and mobility in the small world. This way of setting requirements to join a certain group or be part of a certain world connects to Hartblay's (2020) notion on reconfiguring citizenship and personhood as a special form of disability expertise. I choose to take a look at this with the help of Mossberger, Tolbert & McNeal's (2007) short definition of digital citizenship; the ability to participate in society online. After analyzing the literature and the behavior of my participants in these online groups I would argue that successful participation in these groups depends on the experience of or with disablement/impairments. This experience with disability is shown and validated through disability knowledge, personal connections and recognition (Saltes 2018) as well as the right performance of cultural production (Hartblay 2020).

Although Hartblay does not give a definition of the different types of disability expertise, she notes that cultural production is one of them Hartblay (2020). I would argue that medical language, images that show or symbolize disability and the experiences of it together with expression of emotions liked to disablement or pain are part of this cultural production. Subsequently I would suggest this cultural production is inherently linked to another form of disability expertise which she calls discursive strategies / citizenship and personhood (Hartblay 2020). By being able to show the right cultural clues through the accurate use of language, images and expression of emotions, citizenship and personhood in these parts of the small world is gained. This connects with the statement of Goggin (2016) who says that images and communications are constantly on the move and organize and structure social life (Hannem, Sheller and Urry 2006, 11). I will illustrate how this works by describing my observations of the online behavior of my participants.

During the first explorations of some of the digital spaces of the small world, the use of medical language struck me. For the participants who were most active on Instagram and/or Facebook, Carolien, Christel and Lisa, the use of professional medical language appeared to be normal, as if it is common knowledge to know what these words mean. They used the exact medical name for feeding tubes, medical supplies, impairments and the like, and everybody seemed to know immediately what was meant by that. I often had no idea, which indicated a lack of disability expertise. In order to understand what was being said exactly, I had to deepen my medical knowledge. Why those professional medical terms were preferred became clear to me while writing a report on my sister's disability in order to apply for additional care from the municipality. In the description I had used the words "feeding tube", assuming that the municipality did not have very deep medical knowledge either since they are not a medical institution. I had sent the report to my sister to check it, and after reading it she suggested to change "feeding tube" into "nose-duodenum". When I asked her why she thought that would be better she responded: *"Well, that might make an impression."*

By using official medical language, she tried to make an impression through showing that she knows what she is talking about and capable of understanding things. She was performing her disability expertise just like she does on her social media accounts.

There was more knowledge put on display online, my participants also showed that they knew what life was like when living with a disability through telling about their experiences. For example, Christel posted about how she did not dare to wear eye-catching clothing after she got to use a wheelchair. She described the process of overcoming it and posted a picture of herself sitting in her wheelchair dressed in a colorful flower printed jumpsuit.

In her first post, Carolien stated that she wanted to explain to others what it is like living with her condition. The specific knowledge they had was even captured in their Instagram names, which I won't write out completely for privacy reasons. Lisa showed by her username that she knows what it means to always feel tired. Carolien showed her specialty is knowing what it is like to live with her specific condition in her username. Christel used the same technique, her name points at the expertise of finding and embodying power while using a wheelchair.

However, the knowledge of knowing what it is like to live with disability is not only expressed in words. The images and pictures that are posted often explicitly show mobility aids, feeding tubes, faces with expressions of pain, hospital entries, wounds, tiredness, inaccessibility, new medical supplies, etc. By showing these things, people expose and validate their knowledge on the lived experience of disability, thereby justifying their presence and participation in the small world. It is important to realize that these linguistic and visual expressions of disability experience and disability expertise are not just passively posted and consumed, Instagram, Facebook, and Whatsapp are called social media for a reason. Images and communications structure and influence our social lives in myriad ways (Goggin 2016). The social impact of these communications and images and their effect on mobility is what I will explore in the next part of this thesis.

Building, finding and using new paths

When we analyze the mobilities of people with disabilities, we have to recognize that their mobilities are not just staged from above buts also assembled in complex ways from below (Goggin 2016). Several researchers agree on the statement that the use of mobile devices is increasingly important to the social and physical mobility of disabled people (Goggin 2016; Saltes 2018; Ellis & Kent 2016; Ellis & Goggin 2013). As I elaborated on in the former paragraph, a central reason for why social media is so important for disabled people is that it offers new possibilities for communicating, sharing information and creating content (Ellis &

Goggin 2013). These two arguments on the creation of mobility and the ways in which social media is used come together in Saltes' (2018) work where she states that disabled people create mobility through making connections, accessing information, engaging in advocacy in socio-technical environments. Additionally, based on the accounts of my participants, I would like to contribute to the finding of Saltes (2018) by arguing that next to accessing information and making connections, finding and providing recognition for disability is also crucial to the creation of mobility through technical environments. As Marianne noted, in the small world she finds a level of understanding that she can never possibly find in the big world.

I will now turn to explain how social media was used by my participants to create social and physical mobility in their daily life, that means in the big and small world simultaneously and how making connections, recognition and accessing information (Saltes 2018) allowed them to evaluate the relation between their body, space and others in new ways, ultimately increasing mobility (Titchkosky 2011; Saltes 2018).

Firstly, Saltes (2018) notes that accessing information is an important aspect of how disabled people create mobility in digital environments. There is plenty of information to be found in these online environments, but I would like to add to Saltes (2018) argument by noting that information is not only accessed but also actively produced and shared. As I explained earlier, people continuously share and expose their disability knowledge in order to participate in the digital small world. The things they share form a huge database of information that can be accessed. From effective treatments, where to order the right band aids, which doctor specializes in a certain diagnosis, to how to cope with pain or pity, all this information is readily available. The use of information found in online disability environments to enhance mobility as Saltes (2018) described was also practiced by several of this research' participants. Lisa explained to me that besides reading scientific medical articles, the stories of others helped her recognize symptoms of a disease she had that was not yet diagnosed. This was made even more explicit when I accompanied Carolien for a doctor's appointment. She started to describe her symptoms and pain in a specific way in order to get the doctor to test her on a certain disease which she did not mention explicitly. She knew this had to be done in an extremely subtle manner, exposing your medical knowledge that you got from the internet is often not appreciated by doctors. Lisa once explained to me that one of her doctors did not take her concerns seriously and called her "dr. Google". As Saltes (2018) said, the use of mobile devices shapes potential and actual mobilities and form socio-spatial access and inclusion. These examples show how people with disabilities find specific knowledge online and use their disability expertise to subtly present this knowledge in a medical setting in order to move forward in the medical system. This is just one way in which mobility was established through accessing information. Christel, for example, found and actively shared information around her knowledge on disability which got her involved on matters like accessibility and diversity in the municipality of the city she lives in.

Secondly, Saltes (2018) states that making connections in technical disability environments is also crucial to increasing mobility. Because connections and recognition were often mentioned together by my participants, I put these two aspects together here because they are highly intertwined, but they should not be seen as existing separately from the exposure to and accessing of information. To understand the interconnectedness of connections, recognition and the creation of mobility, it is useful to first look at Cresswell's notion of representation of movement.

Cresswell (2010) explains how our mobility is partly informed by what he calls the socially constructed representation of movement. In short, he means to say that which forms of movement we see represented in certain environments inform us about where and how our bodies should move. Usually disability is represented in a vary stereotypical manner (Ellis & Goggin 2013). But the internet and social media specifically offers disabled people ways to represent disability as they see it (Ellis & Goggin 2013). In the digital environments of the small world it is not the able-bodied way of moving that is predominantly represented, instead it is the disabled body, and it is represented by disabled people themselves. My participants often stated that they felt as if they were alone because they were often the only disabled person in a certain environment. When they enter the digital environment of this changes completely, all of a sudden there is people like them all around. My sister and Hannelore talked to each other on the phone, Hannelore explained how she had often felt alone but that this changed after finding out about the community on Instagram. *"It (the digital small world) brings a lot of positivity, recognition, and gezelligheid*[5]*. And because it is international, there is always someone to talk to. If you are awake at night because of pain, there is always someone in the same situation or in a different time zone who is awake."* she said. It is through the stories and images that are built on disability knowledge that people see themselves represented accurately and thus find recognition. Hannelore was definitely not the

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[5] Gezelligheid is a Dutch word difficult to translate into English. It refers to a feeling of warmth and joy when spending time with other people.

only one to find recognition in the small world. When in severe pain, Carolien called a friend she knew from Instagram and said: *"I'm calling you because you understand, I tell my sister it feels like a severe stomach flu, but you know it is not really like that, you understand".* Additionally, Lisa stated that engaging in specific Whatsapp groups offer her to feel recognition and see similarities in the experience of her disease. In short, in the big world there exist a lack of accurate representation of movement of disabled bodies (Cresswell 2010). But social media offers a place for self-enabled representation of experiences and understandings of disablement and disability, hereby facilitating accurate representation and creating new opportunities for finding recognition. This recognition together with sharing and accessing information formed a crucial base for the emergence of new connections, on which I will further elaborate now.

The images and texts that were posted by my participants were often accompanied by the same hashtags that were linked to their diagnosis, mobility aids or medical supplies. My sister once explained to me that by showing these things of on images, writing about it and labeling her message with commonly used hashtags, her number of followers grew. In other words, by showing her knowledge and experience in different ways, she made more connections. These were not just followers, people who followed each other often grew to be friends and communicated with each other frequently. Lisa told me that she mainly uses Whatsapp to build and stay in contact with people who have a similar disease. *"It feels like real contact and offers me fulfilment*." Marianne said that whenever she feels like residing to the small world would be helpful, she just called someone with a disability. Christel also noted that because she moved through the small world, the people she often encountered there and on disability related events grew to be her friends.

Saltes (2018) noted that making connections in digital environments is also part of the ways in which disabled people establish mobility. This resonates with Titchkosky's (2011) argument in which she notes that the relationship we have we have with others are influential for the places we have access to. In accordance, Goggin (2016) remarks that although we recognize that the shaping of social relationships with digital technologies are closely linked to mobilities, we still do not fully understand how this works. Based on the stories and practices of my participants, I would like to make a humble start to this understanding by acknowledging that the digitally formed social relationships (Goggin 2016), the opportunity to access information, represent disability accurately, and building connections in the small world foster mobility. Although these aspects are highly important in this process, as I have illustrated above, I would like to add the important aspect of finding and providing recognition to this list. Bringing this all together I found that the digital environments of the small world combine offers new ways to evaluate the relation between the disabled body, space, and others (Titchkosky 2011) through accurate self-representation of movement (Cresswell 2010), information, connections (Saltes 2018) and finding and providing recognition. In short, the digital spaces of the small world allow young disabled people to build, find and use new paths, thereby expanding their social and physical mobility in both the small and big world. Although the analysis of the scholars mentioned above resonates with the practices of my participants, I would like to add to them by highlighting that these representations, information, connections and new negotiations of mobility and access are strongly built upon the disability experience and disability expertise that I described in the former paragraph.

Chapter 4 – Finding value, building bridges

On disability expertise & identity in a neoliberal context

Introduction

In the previous chapter I have explained how exclusion leads to the emergence of a second world for disabled people where on the one hand segregation is further established but where there are also spaces where disability experience and expertise is shown, gained and created, where a sense of belonging is established, and where new paths to mobility are build, found and used. Representations of movement, such as the ones posted on social media by disabled people themselves, have the power to influence actual mobilities (Cresswell 2010) while the gained disability expertise and new connections opens up new ways to negotiate access. In other words, people with disabilities are equipped with disability expertise that can be used as fuel to engineer and design daily life, navigate environments, alter mobility, and ultimately facilitate capacity (Hartblay 2020; Hamraie and Fritsch 2019).

In this chapter I will elaborate on these findings and aim to illustrate how the movement through the small world (and the knowledge, connections, recognition and representation that can be found and shared there) and the creation of new paths influences the self-perception of people with disabilities and how this connects to their ideas of social mobility in a capitalist neo-liberal society.

Redefining neoliberal values

"*Maybe you recognize this, having a dream to become this certain thing (thing here refers to having a specific profession) … you didn't know a chronic illness (or disability) would disturb your process. It is extremely painful to, after having tried nonetheless, having to draw the conclusion that (…) you have to say goodbye to this job because it is no longer possible. Your future collapses and you are sitting with yourself at home, what to do now?! How?!* ***What is left of who I am?!****"* – a fragment out of one of the blogs written by Carolien

As we know mobility is strongly linked to identity. Gofman (1963) argued that disabled people are likely having to balance their self-identity with the limiting ideas of what a disabled person is or can be which are being imposed on them through ableism in society. These limiting ideas affect the self-perception of disabled people and "*identity and dignity may be compromised as lowered expectations and a lack of support and understanding limit possibilities*" (Halder 2017, 7) This is reflected in Caroliens' writing above but also in Marianne's quote where she said that regularly she was told that: "*there's nothing in there,* *nothing will ever come out of it and it will never be something*" she said that this was said so often that she was likely to start believing it herself. Hannelore mentioned that she feels like all her dreams were taken away from her by doctors and society when she got a disability. Sophie said that going to school offers her a purpose and a reason to keep moving but she also noted that she often doubts whether it is really useful to go to school. *"Why do I even go to school when you don't know ... what ... the future".* Lisa said that she sees around her how people who become disabled later on in life have trouble accepting it and keep fighting against it because they hold on to certain dreams for the future. The fact that all of the participants articulated in different ways that their future identities were compromised by or conflicted with their disability shows how strong this connection is. This limitation of possibilities and the compromising of self-identity is in my opinion always highly problematic, but it holds specific power for adolescent and young adults who are in a phase of life where identity forming is crucial for becoming productive adults in the society they find themselves in (Steinberg 2011).

To really understand Steinbergs (2011) statement we have to look closer at what is meant by productive adults in a certain society and the ways in which one can become such a productive adult. As the quotes and statements of my participants above already show, self-identity often gets linked to acting out a certain profession in the form of paid employment or being enrolled in an educational program. In a world where disabled people face high unemployment rates, this approach disadvantages them because it makes the (labor)market the only arbiter of opportunities and life chances (Morris 2011 in Mladenov 2015). This is often the case in capitalist neo-liberal countries such as The Netherlands. Mladenov (2015, 446) explains briefly that neoliberalism is a doctrine of radical marketisation that insist on expanding the market logic and principles (self-interest, calculability, competition, efficiency and profit) to all domains of life. This translates into the social attitudes towards people with disabilities in which "their way of doing things is considered disruptive to the "normal" speed, flow or circulation of people, commodities and capital because they "waste" more time and space than they should, maybe reducing profits" (Hansen and Philo 2009, in Saltes 2018). It is true that these processes and ideas influenced my participants self-perception in negative ways. As I mentioned earlier in chapter two, most of my participants actively challenged their value because they thought they generally took more than they had to give back. Luckily, identity is not fixed or given, but rather fluid, always under scrutiny and ever-developing

(Halder 2017) and this scrutinizing of identity was for a large part done through the use of disability expertise.

People with disabilities are equipped with disability expertise that can be used as fuel to engineer and design daily life, navigate environments, alter mobility, and ultimately facilitate capacity (Hartblay 2020; Hamraie and Fritsch 2019). As Fritsch (2015, 44-45) formulates it beautifully, it is about thinking of disability not as something to overcome in order to fit the hegemonic neoliberal social imagination, but as a part of a life worth living by altering what disability is, and what it can be. This is easier said than done, Marianne told me that she is often applauded disproportionally whenever she "overcomes" her disability and does something they thought she never could, like getting her drivers' license. She noted that this praise feels out of place because getting a drivers' license is not something extremely exceptional since most people in The Netherlands get one. However, at the same time, whenever she tells about the things she wishes to accomplish as a person, they tell her she shouldn't want too much because she is disabled after all.

During the municipality meeting Christel explained how she felt like it was hard to gain trust of employers when applying to jobs. At the end of the meeting a short clip was shown in which disabled people played sports and made music, accompanied by the text: "*We're the superhumans*". Telling is the fact that Christel stated before the clip that it is recognition and a sense of being normal that she is looking for. The experience of Marianne and the discourse during the municipality meeting highlights Fritschs' (2015) argument about the importance of imagining disability not as something to overcome, but as something desirable in which we can find value. I would argue that the digital spaces of the small world are an important space where these ideas of disability and value in a neoliberal society were reconfigured by disabled people themselves. Peer (2017) argues that experiences that allow for interaction with other young people with disabilities is a vital part of how disabled people learn to understand disability as a valued form of social diversity. This connects to what has been described in the previous chapter on how social media offers a place and new ways for self-representation, recognition and making connections. To show how this enables social mobility in a neoliberal context it is useful to look at Christels' Instagram post.

The caption under the photo says: *"But what do you do mainly?" Well, no day is the same with me, but there are extra nice challenges! For example, I recently spoke to all managers about why participation is so important and what the added value is of having someone with a disability in your team. It's great to convince people of this, because for many people a job is just a job. For me, it brings a lot more than that. When confronted with a body that doesn't always cooperate, you want to look ahead. Well, I do. It's so cool to be involved at work right now! :D #poweronwheels #participation #speaker #wheelchair #accessibility #presentation #work disability #diversity*

As she states in the part where she introduces herself in chapter one, after becoming disabled she no longer had an idea of what was possible. Christel notes that reading the experiences and ideas of others was very helpful to her finding new possibilities. She found value in her disability and disability expertise by giving inspiration to other disabled people online, as well as informing managers about the advantages of having people with a disability on your team. This shows how representation of movement (Cresswell 2010), recognition, and accessing the disability expertise (Hartblay 2020) informed knowledge of others (Saltes 2018), in this case through the experiences of others that were presented online, shapes actual mobility for

Christel. By seeing and reading what is possible for people with disabilities, Christel came to see possibilities in her own situation, mobilizing her to become a public speaker. Not only did the representation of movement and recognition and knowledge that she found in the small world take her to new places in the work field, the topic she talks about shows how she has come to find a sort of neoliberal value in disability. She now informs managers (and others) about the advantages of having people with disabilities on your team. By telling her story and putting a picture of her doing this on social media, she herself feeds the exposure of disability expertise and representation of movement that Hartblay (2020) and Cresswell (2010) talk about, while actively presenting and embodying a reconfiguration of disability as something desirable and valuable (Fritsch 2015). She claims it is her mission to learn other people to "*think in possibilities, not in limitations*". The possibilities she sees and carries out here I would suggest could be labeled as her personal disability knowledge since the different type of disability expertises, managing pity, creating disability worlds, discussing citizenship & personhood and looking at futurity that Hartblay (2020) distinguishes get combined in her actions and movement. Firstly, she actively discusses the possibilities for citizenship and personhood in a neoliberal society for disabled people by addressing the value of incorporating a person with a disability in a companies' team. By putting herself out there as a knowledgeable public speaker and expert, she manages the view of many other able-bodied people that often don't understand disability and limit possibilities for disabled people (Halder 2016). She takes her message of disability as being something to desire and of value (Fritsch 2015) and links it to futurity (Hartblay 2020); she wants to "*look ahead"* and wants disabled to be equally incorporated in a professional organization. Lastly, her actions and movement as a public speaker where largely informed by moving through what Hartblay (2020) calls "disability worlds" and what I've referred to as the small world. Not only is her work message and movement informed by it, by capturing it and posting it on Instagram coded with hashtags such as #wheelchair #participation and #work disability, she closes the circle and adds to sustaining a world of disability online where disability expertise can thrive.

Her story is the perfect example of how gaining and being exposed to disability expertise by moving through the small world has led her to find and use new paths, making her disability experience and expertise into a desirable and valuable trait that makes her noticeable as a productive adult in a neoliberal context. I choose to dive into Christel's story here, but other participants had comparable experiences. Carolien told me that being engaged in the digital parts of the small world was sometimes conflicting in relation to future perspectives.

"Somehow you see how others with the same disease live and how they too come to be excluded from school and work, that's hard because you hope this will not happen to you. But you also see what others did after that like their own coaching company or blog or working as a volunteer, because of that you also come to see new possibilities". She combined these new possibilities she saw with her disability expertise and by making connections with a girl that has her own coaching company she now writes blogs for her site about what it like living with disablement.

Although I have emphasized the digital spaces of the small world as a crucial factor in the establishment of social mobility here, the physical spaces of the small world are very important as well. These spaces too remain to be a source for disability expertise. Hannelore said that moving through the hospital so frequently and meeting many doctors had discouraged her to become a doctor herself as she had wanted earlier. She now wanted to become a midwife because she felt like she could bring happiness in that position rather than having to take others' dreams away. Marianne decided to go work for the municipality as a consultant on societal support. She felt like she added value to her job because she could empathize and understand the people who were asking for this support (mainly older and disabled people). Sofie decided to go and study health sciences. When I asked her why she had chosen this particular education she told me she had negative experiences with the health care system and wanted to improve it. Her experiences of moving through this system as a person with a disability informed her about what and how things could be done differently. In all of my participants accounts of the future, their experience with disability, their thorough understanding of this category and the expertise they had because they fit into this category had an enormous influence on how they envisioned themselves as working professionals. I would therefore argue, in alignment with Hartblay (2020), Saltes (2018), Peer (2017), Hamraie & Fritsch (2019) that disability expertise, multi-facetted as it is, allows people with disabilities to be active designers of daily life and to re-imagine disability as something valuable and productive. It is true what Halder (2017) argued about how identity may be compromised by the ideas of disability that persist in society that result in limitations and a lack of understanding. However, I would like to add to his statement by arguing that this limitation and lack of understanding can also fuel new self-identifications that I would not label as compromised because these new ideas about identity are based on valuing and desiring disability. Disabled people can come to see their disability not as merely limiting to become a "productive" adult in a neo-liberal society, they can come to see it as the exact thing that makes them valuable and productive, thereby opposing dominant ideas of disability in society that labels them as slowing down the flow of people things and capital and reducing profits (Hamraie & Fritsch 2019).

Interglobal networks

As illustrated in chapter three and the former paragraph, movement through both the physical and digital spaces of the small world is an important, though by no means the sole, factor in gaining disability expertise. This expertise, as I've stressed, is highly beneficial in the process of finding value in disability and incorporating it into positive self-identities in a neoliberal, capitalistic context. This, however, does not mean that establishing social mobility for people with disabilities and learning to value disability is done solely by disabled people themselves inside the small world. I will argue that to establish social mobility in the big world, disabled people actively build interglobal networks to assist in and support their movement. By interglobal networks I mean a network that is a combination of skills and people both from the small and the big world. This resonates with the different layers of Titchkosky's (2011) statements. Firstly, as explained in chapter two, mobility is tightly linked to access (Titchkosky 2011). Titchkosky defines access as a complicated manner of perceiving the relation between bodies, other people and the place one finds him/herself in (Titchkosky 2011). In chapter two I have already explained how these physical places and social perceptions are heavily entrenched with ableism which results in the occurrence and persistence of naturalized and justified social and physical barriers that limit physical and social mobility for disabled people (Titchkosky 2011). Gaining disability expertise and moving through the small world does not take these barriers away. However, where I noted in chapter two that ableist barriers are often also naturalized and justified by disabled people themselves, I would also argue that learning to use interglobal networks through disability expertise does allow for new ways to relate to and conquer them, which I will now turn to explain.

As Cresswell (2010) notes mobility is tightly linked to the production of power and relations of domination. Immobility as well is made by unequal distribution of power; "*some move in such a way that others get fixed in place*" (Cresswell 2010, 21). Additionally, Fritsch (2015) notes that despite the fact that people with disabilities are increasingly incorporated in work environments, the hegemonic view of disability remains one in which disability is linked to dependency. In this way able-bodied people are often the ones who are perceived more powerful when it comes to mobility. Disabled people are aware of this relation. By continuously moving through the small and big world simultaneously, they know that mobility is a resource that can be accessed in different ways (Cresswell 2010), and they realize that using the power of able-bodied people is part of the ways in which mobility can be accessed. Just like the participants in Hartblay's (2020) study, my participants used the power and bodies of able-bodied people as an extension of their own. This is where the use of interglobal networks emerges. Carolien put it clearly into words by stating that the small world teaches her where to go and how to behave to get the things she needs. But, when she encounters social or physical barriers either in getting there or moving and navigating the destination, she makes use of an able-bodied person in order to change the relationship she has to these barriers. This sounds quite abstract but becomes clearer through the stories of the participants. While looking for ways to go and study health science, Sofie asked her mom to attend the open day at the university. In this manner she made use of her mom's body in order to get to a place that would contribute to her social mobility. Sofie however was by no means passive or not present in this act. She simultaneously made connections online with students with a disability that were already enrolled in this university program to gather information that was specifically linked to studying with a disability. When Carolien was invited to go and look at a wheelchair accustomed house she asked me to go in her place because her bodily condition did not allow for her to physically go there. In the conversations with the organization that would determine whether she had all the criteria to have the right to live in this house, she consciously took the lead and expressed in myriad subtle ways that she was "disabled enough" to live there. She listed all her symptoms, diagnosis, and demands for help "*on automatic pilot*". Less automatically but rather careful and refined she exposed that she understood what it is like to have a physical disability by explaining how she saw her relation to caregivers. She said that she saw them as their hands and legs, but not her brain. When the able-bodied interviewer asked for her social security number she looked it up on her phone, showing she is in charge of and capable of doing her own administration, but instead of reading the number out loud she handed her phone to the woman who was sitting at least 1.5 meters away. By doing so she exposed the dystonia in her arm explicitly. This connects to (Kasnitz 2020) who says: *"Like others, I continually invent micro affordances and direct accommodations. There is a reason I accentuate my odd gait and hold my ticket in my "bad" hand when boarding a plane: I want the preboarding affordance".* This continuous inventing of micro affordances and directing accommodations is what Hartblay (2020) labeled disability expertise. As I mentioned many times before it is through this expertise disabled people know how to alter the relationship with the space and people around them either through their own bodies and behavior or directing the behavior and bodies of able-bodied people, ultimately altering power relations and creating mobility (Titchkosky 2011; Hartblay 2020; Kasnitz 2020; Cresswell 2010). This expertise is developed through the experience of both physical and social barriers, being excluded and moving through two worlds simultaneously. From doing so, the participants explained it teaches them how to be patient, empathetic and most of all, to think in possibilities. They know how to connect the small and big world through building interglobal networks and use them to alter socio-spatial relationships in order to move forward. This special skill is key to finding their self-worth and to be socially mobile in a neo-liberal society. They enact this skill by taking on employment that also places them right in the middle of the big and small world as professionals. Be it as a disability consultant for a municipality (Marianne), a blog writer raising awareness (Carolien), studying health sciences and striving to change the healthcare system (Sofie), translating experiences with disability into paintings (Yuna), a public speaker on accessibility and inclusion (Christel) or becoming an advocate for disability rights (Marianne).

Chapter 5 – Conclusions

This research is a response to Hartblay's (2020) call to claim disability anthropology and use it to gain a deeper understanding of the ways disabled people mobilize power in different cultural configurations of systems of ableism. Little literature is available in which there is an ethnographic exploration of how disabled people are active mobilizers of power and effective in creating social mobility. In this thesis I have sought to do exactly that, providing an ethnographic account of how young disabled people use disability expertise to establish social mobility in a context based on ableism and neo-liberal capitalistic values.

The objective was to answer the following question: How do young people with disabilities use their disability expertise to establish social mobility in a world that consists of environments based on ableism? In search of an answer the literature and empirical data led me to analyze and connect the concepts of mobility, ableism, disability. Special attention has been given to the notion of disability expertise (Hartblay 2020) which has proven to be a helpful scope to look and interpret the actions and experiences of the participants. With this research I have shown that mobility is not just limited through the on ableism-based obstacles, but also actively negotiated and created in complex assemblages by disabled people themselves.

From the research that has been carried out, multiple conclusions can be drawn that together form the answer to the main research question.

Firstly it appears that ableism is omnipresent in the world around us and actively creates physical and social barriers that make it hard for people with disabilities to move around physically as well as socially. Since the ways in which we move and where we move influence our self- and perceived identities, it also influences to which places and social groups we belong and to which we do not (Titchkosky 2011, Jaffe 2016). I have argued that ableism is in fact so deeply rooted in our society that it leads disabled people to often naturalize and justify the barriers and exclusion they face. In addition, they will often rely on able-bodied peers to conquer barriers because they experience how they can alter the negative socio-spatial relationship the disabled body is usually experiencing. Through this naturalization of barriers and exclusion and having to have mobility facilitated by able-bodied people, the ableism that forms and sustains these barriers is largely kept in place. The relationship between exclusion and physical barriers is however not that simple or linear, the social ideas that exist in society about disability limit physical movement too. This proves that physical access gets continuously interlinked with social organizations of participation and belonging (Saltes 2018, 82). The ableist ideas and environments create exclusionary spaces that fosters a need for spaces where disabled people do belong and where disability is accommodated for.

Consequently, a parallel world, "the small world" emerges where disability is free to exist and specifically accommodated for. The small world partly consists of physical manifestations which are often not created by disabled people themselves and are oftentimes not joined on a voluntary basis. The other part of the small world exists of digital environments in which knowledge, connections and recognition can be found and shared. This is where a lot of disability expertise is enacted and gained through making personal connections with other disabled people and accessing knowledge (Saltes 2018). To define disability expertise I have followed Hartblay's (2020) definition that consider disability-expertise to be the specific knowledge that people with disabilities develop and enact about unconventional forms of agency, cultural norms, and relationships between identity, the body and designed worlds. By analyzing the role of disability expertise in the digital spaces of the small world I have argued that besides the connections and access to knowledge, it is also the opportunity for accurate representation of movement and disability (Cresswell 2010) and gaining disability expertise that allows for new configurations of access by building, finding and using new paths that expand social and physical mobility in both the big and small world.

Lastly, I have looked at the ways in which these new paths and mobilities manifest itself in a neoliberal, capitalist context. Namely, moving through the small world offers recognition and a representation of possibilities that allows people with disabilities to find value and desirability in disability whereas in their value and identity often get compromised in the big world because they are perceived to be less productive citizens. I have argued in line with Hartblay (2020), Saltes (2018), Peer (2017), Hamraie & Fritsch (2019) that disability expertise, in multi-directional ways, allows people with disabilities to be active designers of daily life and to re-imagine disability as something valuable and productive. To act upon this new identification of disability the big and small world need to be connected. Disabled people are exceptionally good at this because, as I have previously shown, they know how to negotiate access and mobility in both of these worlds by either altering their own behavior or instructing the behavior and bodies of able-bodied people, thereby reconfiguring power relations and creating mobility (Titchkosky 2011; Hartblay 2020; Kasnitz 2020; Cresswell 2010). In this manner they create what I call interglobal networks, a set of combined skills and social relations that are informed by disability expertise and experience and that functions to establish physical and social mobility in the big world.

In short, through constant negotiation of and encounters with obstacles, and a continuous movement through two worlds, disabled people develop disability expertise that enables them to connect the two worlds and think in possibilities. This ability to connect both worlds is translated into newfound value in a neo-liberal society that incorporates disability not as something to overcome, but something productive that has value and can even be desirable. This proves how disability expertise, building interglobal networks and thinking in possibilities is crucial to the establishment of social mobility for young disabled people in The Netherlands. They have much to offer in terms of improving the ways in which we design our healthcare system, physical world and social relationships, and it becomes time we actively value, listen to and act upon their knowledge.

Although there is still an enormous amount of practices, ideas and knowledge to be explored, this thesis is hopefully one of many explorations to come to broaden our understanding of the complex relationship between disablement and the establishment of social mobility through complex assemblages of social relationships and embodied practices of mobility. The findings can be of practical societal relevance since it opens up ways to move away from a point of view that considers disability as forced immobility. Instead, it reveals that contemporary mobilities of disabled people are actively reconfigured and tuning into them has the potential to make society more accommodating and appreciating for the value that disability and disabled people have to offer us, hopefully enabling us to offer equal opportunities for social futures.

Further research could further enlarge our understandings and I would encourage anthropologists specifically to use their ethnographic skillset in order to get a better understanding of the different forms of disability expertise and its' role in the lived experiences and realities of disabled people as well as how they relate to the bigger systems that shape our society as a whole.

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