UPPSALA
UNIVERSITET

(In)visible bodies
An Anthropological Study on Systematic Ableism, Embodiment, and Identity

Abstract

Uppsala is the fourth biggest city in Sweden and is known for having a rich cultural life, beautiful landscapes, and a long history. Because of how Uppsala is built, infrastructure and urban planning limit people with mobility restrictions from being able to access shops, and well-visited locations due to the absence of accessibility adjustments or poorly constructed routes. This ethnographic study takes a phenomenological approach to emphasize the experiences and perspectives of those affected by mobility restrictions and those who feel peripheral in society in multiple areas, ranging from infrastructure to social stigma due to a society built upon systematic ableism. The thesis thus explores the body as a symbol and the experience of being (in)visible. The physical body's presence is acknowledged while the stigma of being disabled, and the social and environmental barriers one encounters when navigating public areas designed for normative bodies, remain invisible.

Keywords: Embodiment, ableism, impairments, identity, agency.

Table of Contents

1. A memory and a source of inspiration

I recall a chilly winter afternoon a few years ago when I worked as a support assistant and caregiver for a man with a neuropsychiatric condition and a physical disability that made him unable to walk and thus needed the use of a wheelchair. The man had a doctor's appointment, and one of my tasks that day was to accompany him to the healthcare center institute. Before the appointment, I was informed by the staff over the phone that the center was on the second floor of a massive building built of gray brick. When we got to the gray building's door, we faced an obstacle. To enter the building, one had to ascend four steps up a stone staircase and then use the elevators to reach the healthcare center. The man I was assisting could not get up those stairs. How can there not be a wheelchair ramp at a medical facility? How insufficient is the state at helping people who need accessibility modifications if a healthcare institution is not prepared to install a wheelchair ramp so patients may attend their appointments?

Reflecting on this memory and the struggles faced by people with disabilities in their daily lives made it clear that the city's material design and placemaking are not built for everyone. This had me reflect upon what the reason behind this may be, since it is difficult to believe that it is because of a lack of funds, or that they did not consider a ramp to be necessary. This raises questions about whether it is intentional or not, considering the amount of mobility- and restrictions aspects there are, both visually and discursively, and how they articulate with many other societal phenomena. Especially since ramps are aesthetic issues, which makes it unclear whether a wheelchair ramp is acceptable to install outside an old building in the city center according to the city plan. The questions are numerous, and this thesis investigates this phenomenon through an anthropological approach and lens to answer this ambiguity.

2. Introduction

2.1 Background and Previous Research

When the train arrives at Uppsala's central station just before dusk, the wind is blowing chilly in the late fall, and the sound of the trains is noisily squealing. Due to the fast-paced rhythm and the need to manage to catch the connecting buses, go back to work in time, or be in a rush for no specific reason, several people are swarming out of the train and are millimeters away from colliding with one another. People are squeezing past each other to use the station's only functioning escalator or are rushing down the stone steps to exit the platform. An old lady, around 70 years old, with a gray scarf blowing in the wind, seems to be stressed while struggling to navigate herself through the masses. She seems almost out of place, not fitting into the frame and the conception of an afternoon rush in a big city.

In the 1960s and 1970s, people with disabilities in the US fought for equal access to opportunities, healthcare, and employment as normative American citizens. Their struggle culminated in a global movement that put disability on the map (Fleischer and Zames, 2001). This movement sparked interest among anthropologists to study disability as a cultural phenomenon in specific contexts (Ruby-Reid Cunningham 2009, 100). Even though the study of disability within the discipline of anthropology is relatively recent, anthropologists have long been intrigued by understanding how different cultures perceive and interpret the concept of "the other" as well as what distinguishes a group as "others" (ibid.). In our contemporary society, city management- and planning are shaping ideals through infrastructural processes designed for those characterized as able-bodied and normative. This causes discrimination against people who have disabilities and do not fit into the frame of society's ideal picture of the human body. This leads to environmental obstacles such as non-automatically opening doors, stairs without ramps, and poorly constructed routes and passages. These obstacles also become social barriers because one is supposed to adjust to environmental and infrastructural changes but cannot do so because of one's impairments. This translates into social stigma and distress, where one is not able to perform as society requires one to do. This thesis aims to provide insight into how these conditions are experienced by presenting the narratives and thoughts of three people, whom I will refer to as Jonas, David, and Karl who share their experiences of battling environmental- and social obstacles while navigating their lives in a wheelchair in a society that favors an ableist environment.

2.2 Purpose and Research Questions

During my fieldwork, I have delved into the challenges individuals with mobility impairments face in Uppsala. I have explored the societal and environmental barriers that my informants encounter when navigating a world that favors the "able-bodied". I have tried to explain and uncover the reasons behind the marginalization of people with physical disabilities in a society that claims to value inclusivity. My purpose and aim have been to explore and understand how people with disabilities experience the liminal phase of being neither well nor ill and how individuals with impairments are integrated and discriminated against in society by emphasizing the important role of the physical body. By exploring the feeling of being the "other," and how it is to be physically disabled, we can better understand how exclusion from groups or infrastructure and urban planning can occur due to perceived differences and perspectives on the body. This reflection thus results in two main questions that I want to respond to. How are social and environmental challenges experienced by individuals with mobility restrictions in Uppsala? And what importance does the body have in social contexts?

2.3 Theoretical Framework

To shed light on the context of this study, anthropological theories on ableism, body, and identity will be presented. These theoretical perspectives serve as a guide and play an important role in analyzing the empirical material. Ableism is the primary focus of this thesis, whereas theories on body and identity are theoretical guides to the phenomenological experience of being disabled, as well as how the body is perceived as a symbol from an emic perspective. There are therefore two contrasts here, what the embodied experience is, how the body is symbolically perceived, and what it conveys in a social setting.

Ableism

To be referred to socially or juridically as physically disabled, there has to be a dichotomy and something that suggests that there are able-bodied and physically functioning people. What does it mean to be able, and what does it mean to be disabled? An able-bodied individual, as I will call people who are physically normative in this text, is a person who lives a life in a world designed for those who are not hindered and those who manage to sustain and adapt to environmental and material changes. Since most people who are considered able-bodied can physically adapt to a constantly changing environment, abled-bodied people are thus considered normative. Being disabled, on the other hand, discursively and physically, is not being able to perform or manage to live up to the expectations of what it means to be able-bodied and is thus being labeled as disabled to do things considered normative (Devlieger 2018). This structural condition is known as ableism and it can be discriminatory, though not always deliberately, towards people who have disabilities.

Embodiment and symbolism

The concept of embodiment provides valuable insight into the normative body as a societal standard by focusing on the concept of ableism and why people with disabilities are frequently perceived as "others". Embodiment theory in anthropology posits that the body plays a crucial role in shaping our experiences by helping us make sense of the world around us. It emphasizes the importance of considering the body as a fundamental aspect of human experience, showing how our physical bodies are intertwined and linked, which mediate our social, cultural, and environmental contexts (Jarrett and Throop 2023). Bodies are, therefore, a subject of culture, rather than an object of culture, as put forward by Thomas Csordas (1990, 5). In contrast to the concept of embodiment and the "lived experience", American anthropologist Clifford Geertz (1993) stressed that symbols act as a

vehicle used to convey meaning, and whether it is an abstract or an embodied symbol is of no difference in this context (ibid., 1993). Since we cannot perceive what is going on inside someone else's mind, the body is a symbol for representation, and as a locus for actions such as mobility and normativity.

Agency

Agency is defined as the ability of a person to act freely and have the capacity to make their own decisions (Barker 2005). Individual studies of agency are possible, but agency is always in conjunction with the social collective, as everyone expresses their agency to different extents. However, social constraints can restrict the power of expressing one's agency because everybody interacts with the structural framework of the society in which they inhabit and live. According to Michel Foucault, a prominent philosopher of power dynamics and societal structures, stressed that agency is a concept that can be understood in the context of power relations (Foucault 1982, 778). That is, the concept of agency becomes embodied as a result of how power is inscribed on and exerted by the body (ibid., 13ff).

Identity

Identity encompasses multiple areas of cultural and societal complexities. There have been different interpretations of the term within anthropology. The following interpretation by anthropologist Golubovic is the one that I have used during this thesis "the identification with one's own culture and self-reflection of the way one is to live in a given socio-cultural environment" (Golubovic 2010, 26). Golubovic suggests that identities are both cultural constructs within a shared society, and personal identifications that are intertwined and intersubjective. Intersubjectivity relates to the conscious and unconscious interplay between individuals in a society (Jackson 2017, 130). Concerning the theory of embodiment, identity plays a role in how our bodies are perceived as distinct entities in social, medical and political contexts, and how these distinct concepts differentiate from the concept of ourselves (Csordas 1994, 5). This means that we have multiple identities that are being defined by different actors of society in various social contexts.

2.4 Research Methodology

For this study, I have conducted interviews with three people. I will refer to them using the pseudonyms Jonas, Karl, and David for anonymity reasons. Two of these interviews have been conducted in combination with participant observations. The interviews and participant observations explored various physical places, such as the Uppsala town square, a nursing home, and a workplace. The following section outlines how this study has been conducted, as well as what methods have been used to collect the necessary data to adequately grasp their experiences of being seated in a wheelchair.

Hsieh and Shannon (2005) suggest that when focusing on interviews and informants' experiences, using a conventional methodological style in a qualitative text analysis with an inductive type of research is adequate for the field one is methodologically approaching (2005, 1281). This is an appropriate method, especially for studies that mainly focus on phenomenological experiences. When using an inductive methodology, the researcher starts by empirically observing and finding patterns in what is observed and theorizing based on those patterns (Hsieh & Shannon, 1279) or understanding perspectives from the "native point of view" (Howell, 2018). This approach fits well, especially since mobility impairment and ableism as cultural and social phenomena in anthropology are still relatively unexplored (Durban 2021; Reid-Cunningham 2019, 100). And as both Andersen and Solheim (2015), and Pink and Morgan (2013) argue, when conducting a short- term ethnography, one has to be concise and focus on carefully chosen details to examine, rather than approaching the entire field (Pink and Morgan 2013, 356). To avoid overlooking or excluding details from others' experiences, it is necessary to focus on specific information and interpret it carefully when analyzing collected data. This is why I have thoroughly focused on the informants' subjective experiences in a cultural context and will not be discussing and focusing on the physical condition per se that my informants have, even though that is an important question. The methods primarily used during this work are in-depth semi-structured interviews and participant observations.

Interviews

These weeks of fieldwork have resulted in invaluable learning from the interlocutors Jonas, Karl, and David. The primary methods that have been used to obtain information have consisted of interviews, which have resulted in an in-depth analysis of the respondents' lives and the challenges of being physically impaired. The questions have thus been focusing on the experience of sitting in a

wheelchair, and what social- and environmental obstacles they face. For this study, semi-structured interviews have been used, whose questions are part pre-determined and part open, giving the respondent the flexibility to answer open-ended formulated questions with answers that best suit them, or where the respondent may interpret the questions as they wish. As Skinner states, " […] an interview whose purpose is to obtain descriptions of the life world of the interviewee concerning interpreting the meaning of the described phenomena" (Skinner 2012, 8). My purpose has thus not forced pre-existing categories that the interviewee is required to adapt to, but as a guide to structure the interview as a whole.

Observations and Participant Observation

In combination with interviews, I have been conducting observations by looking at accessibility options at train stations and town squares, as well as observing people find mobility patterns in those places. I have also conducted participant observations together with one informant using a methodology called "walk-and-talk" where he has shown me how he moves through Uppsala, what routes he takes, and what obstacles he faces while communicating with me and expressing his feelings at the moment.

During the interview sessions, I have found that conducting a "walk-and-talk" session can provide a different perspective on how people navigate through space by showing it, rather than just discussing it. This method involves accompanying the interviewee while in motion and having a conversation in a more casual and comfortable setting. The reason why I prefer this method is not only because it provides a more relaxed approach, which can contribute to a more easygoing interview. The places we visit during a "walk-and-talk" session can reveal much about the person being interviewed. Pranka (2020) argues that places are closely tied to memories and experiences, and by guiding someone to different places, the interviewer can acquire insight into the interviewee's experiences and how they perceive the world around them. How individuals traverse through town squares for instance, and what routes they take are not always deliberate decisions. Specific routes originate in personal memories and experiences, also embodied ones, that influence behaviors. By exploring these aspects of the experience of embodied and situated character, we can better understand what it is like to live differently from our own lives (Crapanzano 2003), as well as understand the limits and possibilities of living in a particular type of body (Jackson 1977).

2.5 Ethical Reflections

As I am considered an able-bodied person I am perceived as normative by society, or at least manage to pass as a normative person because of my ability to navigate and move freely in communal and public spaces. I do not find myself struggling physically while navigating the physical world. Several years ago, I worked as a caregiver and support assistant for individuals with disabilities who had various physical and cognitive challenges. These individuals were entitled to community support services to assist them daily. I believe that my years of experience as a long-time worker as an assistant, which involved providing physical support and emotional counseling, enable me to better understand and interpret the stories and lived realities of this study's participants. As such, I have aimed to try to justify my interpretations of my informant's stories and statements, do my best to be reflective on the data, and be self-aware when analyzing and presenting the information that has been gathered.

In the planning stage, while conducting the fieldwork, and interpreting the empirical material, I followed the principles of ethics and principles from the American Anthropological Association (AAA), such as being open- and honest regarding my work while reaching out to the informants (Allen 1997; Calvey 2008). All participants for this study were also informed and aware of the study's aims, at what academic level, and where it would be posted, and they gave their consent to participate (AAA n.d). I reached out to the interlocutors by contacting a private center for people in Uppsala, which arranges activities for people with disabilities. From there, I got the telephone numbers of the participants for this study. When I spoke with them, I gave them a brief overview of my research topic without revealing too much, to prevent my questions from influencing their answers in a biased way. I explained that I was interested in interviewing them to explore the experience of living with a physical disability and gave them a short explanation of my research area, to explore how it is to live with a physical disability. They were also all informed they could reach out to me at any time according to AAA guidelines, to change or withdraw their narratives and stories. All participants found this to be an interesting subject and were willing to participate. Lastly, it is worth mentioning that the interviews for this study were conducted in Swedish but will be translated into English in the text when referring to quotes. I hope to do justice to their words when translating.

2.6 Disposition

This thesis is divided into five chapters that all concern systematic ableism. In chapter 3 I explore the experience of being disabled drawing from Jonas and Karl's subjective experiences, and how the condition correlates with both physical- and emotional struggles. To investigate this relationship, I examine their statements and narratives as well as those from Thomas Csordas (2011) and medical ontology by Anne-Marie Mol (2003). I aim to show the importance of different abled- bodies with mobility disabilities and the various ways in which individuals navigate their lives, negotiate, and define themselves in an ableist world, to gain a deeper understanding of their lived realities.

In chapter 4, I dive deeper into Jonas and David's identities. I examine the shaping and overlapping of identities, and what social factors contribute to that construction. Further, I explore the intricate relationship between the individual and their social identity considering sickness, what societal consequences the ambiguous theory of the "sick role" has, and how it affects the experience of the self.

In chapter 5, I emphasize how the municipality is working to resolve accessibility barriers and the ambiguity and double bias that follow them. I explore whether Karl and David see the municipality's efforts as worth looking forward to or whether they see them as empty words and promises. I aim to show their main concern and share their stories of how they have been treated by the municipality, and what outcomes and efforts their strive for accessibility adjustments have led to.

3. Navigating Ableist Structures

3.1 Embodied Experiences

When I first met Jonas in 2023, we strolled through Uppsala's town square amidst a crowd of people. Aside from the sound of Jonas' wheelchair clicking as it impacted the cobblestone walkway beneath us, we could hear laughter and conversation from people walking by as the drizzle of rain fell on us. We both discussed how cold it was, and how strange that the snow had not fallen yet, considering it was mid-November. But, as we both agreed, Swedes always complain about the weather, whether warm or cold, it is never "just right". I had never met or talked to Jonas before I asked him if we could meet up for a coffee to discuss how he experiences living with physical impairments, which he gladly agreed to. Jonas was born with cerebral palsy, which is a neurological condition that affects the body's movement and muscle coordination. Due to his condition, he also has hemiplegia, which leaves half of his body paralyzed. I was interested to learn about Jonas' experiences navigating the world in a wheelchair, especially in places not designed for easy accessibility with stairs, non-automatic doors, and uneven walkways.

During our stroll, the elderly man looked up at me with his blue eyes and opened up about his experiences of sitting in a wheelchair during most of his waking hours, apart from the obstacles he faced. The problem was not the disability itself that made him use a wheelchair, but how poor the city construction is and how people, in general, are careless towards people with disabilities. Jonas delved into the dilemma of being perceived as disabled by society, as well as what social implications come with it. He explained that apart from restrictions that come with particular conditions such as movement and spatiality, he also feels socially displaced in a society that is not designed for people who need the use of a wheelchair. This feeling is leading to a sense of deviance.

> The city is generally only adjusted for pedestrians and prams. But, if someone enters a store with a wider wheelchair, it can become difficult to pass through doors and navigate in stores. Especially in the store "Normal", where it is hopeless to enter with a wheelchair where one has to move around the entire store to get out because there is not enough room to physically maneuver. So, I would say it is a problem for us to enter those kinds of stores.

What Jonas describes is a prominent example of how the body becomes regulated in everyday life, and how the stores are not adjusted to people with disabilities. This leads to him avoiding certain

places he wishes to visit. The store "Normal" is not the only store and the single issue in Uppsala, but a small fraction and a symbol of larger societal issues regarding how one moves- and enters through environmental boundaries. The feeling of not being able to navigate life as one wishes causes distress and affects one's sense of control since agency is not only embedded in our minds but also in our bodily movements. As Thomas Csordas argues, the ability to move through space is not just a physical act but also a way we express our agency (2011, 147), as well as our capacity to exert control over ourselves and our environment (ibid. 2011, 148). These perspectives made me reflect on Jonas's experience as a permanent wheelchair user, and his stories about the challenges he faces when visiting stores such as "Normal" in Uppsala. When I asked Jonas if "Normal" is a store he usually wants to visit, he said that he does not want to visit it anymore since he became a permanent wheelchair user a few years ago and that the store has too many accessibility limits. He also mentions that "One has to be careful not to destroy or tear down anything in the store" because one is in a wheelchair when squeezing through and turning around in narrow spaces.

For Jonas, visiting and moving through the store becomes a manifestation of his agency and control over the environment. The physical limitations of the store do not only present practical challenges but also emotional ones for him. He struggles with societal expectations of traversing a space that was not designed to be accessible for his non-normative body, such as narrow alleys. Ableist structures often result in people with disabilities feeling subordinated in society (Probst and Tabin 2019, 2). What this entails is that individuals with disabilities have to balance between meeting societal norms while being in a non-normative body, expected to do normative things. Not being able to meet norms may cause a feeling of shame (ibid.) or fear of failure resulting in shame, which is common when one does not meet societal expectations, such as knocking something over because of bodily actions. Moreover, bodies and bodily functions are projections of cultural discourse and symbols, and not of the individual oneself (Turner 1994, 44). The body is not only a site for agency and control but also a representation of society, where those who are considered able are the representational subjects. In society, those who are considered the most representative subjects live with certain privileges that are not available to those who are not, such as passing socially and how one navigates materially as a normative and functioning person. Physical impairments do not just affect the body, but also the mind, because one cannot adjust their body to fit into an idealized societal setting. This creates obstacles within oneself and the environment. Therefore, disability can be a significant challenge where the body does not operate as the mind wants it to. However, disability is made even more challenging by ableist structures and societal attitudes toward disability, since they create unrealistic expectations for normalcy and mobility, which are impossible

for some individuals to achieve. Judging by Jonas's experience and stories, the store's physical space becomes symbolic of broader societal expectations, which reflects the struggle individuals with disabilities face in balancing norms and their non-normative bodies.

3.2 Social Stigma and Prejudice

Back in the day, in comparison to how it is now, Jonas said, "People such as us who live with disabilities were supposed to be locked up in institutions and were not permitted to be with other people […]. People were looking at us as if we were stupid because we walked so weirdly, or because we moved differently. Today, I can understand that children look at me because I am in a wheelchair. After all, they are curious to know things. So that they are looking at me does not concern me.

Sweden has a disturbing history of systematically mistreating people with disabilities in the past. Until 1980, there were mental hospitals and institutions where individuals with cognitive impairments were forced to live in facilities designed for mentally ill patients (Leena-Karlsson & Bolling 10ff). One of these facilities, called Beckomberga, represents a particularly dark and tragic chapter in Swedish history. At Beckomberga, people who were considered "insane" could be subjected to lobotomies or other experimental treatments, such as long- baths lasting up to twenty-four hours to help the patient "calm down" (Ögren 2006). It is important to note that not everyone with impairments was institutionalized like those at Beckomberga, but the attitude towards people with disabilities at the time was in general aligned with the hegemonic discourse that people who were cognitively impaired should be treated as mentally insane and could be cured.

When adults look at Jonas things are different, he said. During his adolescent years, Jonas did not utilize a wheelchair. He claimed that as he was moving around, "people thought I was drunk, a drunk 15-year-old who was high on drugs", because of his cerebral palsy. Even now, when he is in his late sixties, it is evident that these prior experiences still affect him. As we moved across Svartbäcksgatan, Jonas told me he wanted to show me what it is like to get around town in a wheelchair. Even though it was his initiative to move through a crowded space, I took note of his struggle to get across town. People flooded from two directions, paying no attention to their surroundings, particularly those in our peripheral visual field who had their faces glued to their phones, not paying attention to the man who was coming at them at breast's height in a wheelchair. Jonas told me that people often perceive him as "someone who's in their way" when he crosses their

path with the 65 centimeters width of his wheelchair. As we stopped before a cross-path, Jonas said that prams are more socially acceptable, and society is more adjusted to prams than to wheelchair users and other physical disabilities, such as blindness. Sometimes, Jonas experiences the interactions as if these people clearly think he is "stupid" due to his condition, which is often expressed by high sighs and grunts, and even yelling when he crosses pedestrians' paths. However, from an ableist point of view, Jonas can be considered "cognitively developed" as his disability does not affect his cognitive functions, and those who are familiar with him know this.

As we continued traversing through town, we moved amid people on the commercial high street in Uppsala city, Jonas abruptly turned right and led me down to a side street. There were not as many pedestrians here, in contrast to the flooding of people on the main street. It struck me that, if prams are not considered "in their way", it is not due to the width of his wheelchair that people believe he is in their way. Rather, the issue is that mobility and the body are normally perceived as a symbol that one should be able to control in one's environment. As Devlinger posits, it is not the disability itself that is the issue, but rather "the incompatibility of impaired bodies with social norms and material conditions" (Devlinger 2018, 1). This theory of the body implies that a grown man in a wheelchair is considered non-normative and deviating from social norms, causing frustration among busy-looking pedestrians. Meanwhile, infants in prams are considered normal and are therefore socially normative and more tolerable because a child is supposed to not be able to physically control themselves. As such, we cannot know for sure that others perceive Jonas as cognitively impaired, but he is still experiencing a feeling of being deviant from others that may cause one to feel "stupid", according to Devlinger's theory (2018).

To further examine and understand why Jonas believes people perceive him as cognitively impaired, it is important to categorize his condition into three distinct concepts- illness, disease, and sickness. In medical anthropology, illness refers to the patient's experience of the condition itself, while disease is the pathological or biological definition of the condition made by a medical practitioner, such as a doctor. Finally, sickness describes the societal perspective of the condition that is influenced by cultural beliefs and deviance from normativity that causes reactions to the condition, which can cause stigma (Mol 2003, 7ff). When Jonas told me that people perceived him as "stupid", it may have implied from a sickness perspective that he is considered deviant and does not fit into the frame of an idealized society where normativity and able-bodies are considered desirable. Him, sitting in a wheelchair, and not being able to mobilize as he wishes create prejudices and misconceptions of his condition despite his cognitive abilities being unaffected.

This is primarily due to societal attitudes towards those who are considered different or deviant. People with disabilities are often stereotyped and clustered together, and the wheelchair may be seen as a symbol of cognitive underdevelopment, which is a common misconception. When Jonas expressed his fear of knocking things over in the store, it is possible that he was worried about being perceived as "stupid" due to the potentially embarrassing action of displacing carefully arranged things, especially considering that he is in a wheelchair, which he feels is already causing stigma.

When Jonas made that statement, it reminded me of when I sat down with Karl that same week. I met Karl outside a nursing facility that he occasionally visits for their nice coffee. Karl, a tall and surprisingly athletic man for a man in his late sixties, had just guided me into a room with white walls and basic furnishing. There were no tables but a couple of chairs on either side. He explained that he had chosen this location because it was somewhat private and offered shelter from the cold outside. As we sat next to each other with our coats still on to keep warm, he told me that the brain hemorrhage he suffered during surgery when he was in his early sixties had greatly affected him. The hemorrhage rendered him physically disabled and, thus, required the use of a wheelchair when traversing space. Karl told me a story of when he was on a stroll one day and was stopped by the police for seeming to be "confused" when he was sitting motionless in his electrical wheelchair on the sidewalk. Karl told me that the police probably thought he lived in a nearby facility for elders with dementia and that he was lost. However, he was stuck on the sidewalk because there was no sunken curbside spot, and his only option was to either stay there or risk getting injured while trying to cross the elevated curbside. What I find interesting is that Karl believes he was stopped because the police automatically perceived him as a confused old man because he was sitting motionless in the middle of the winter, and not because he was stuck on the pavement trying to understand how to get across. This described situation highlights how bodily norms are "inscribed" in the body (Foucault 1987, 13ff) and how it affects how we perceive and identify ourselves and others.

4. Identity and Storytelling

4.1 Social Alienation and Sickness

The concept of identity is complex and can be understood in different ways. Since each individual has a unique understanding of themselves, defining a universal explanation of identity is impossible. Identity is dependent on the social context in which one identifies and is identified. It is thus a multi-faceted concept. Although it is challenging to define identity, studying how individuals interact with their environment and how life experiences affect their perception of life can help us better understand it. Anthropologist Michael Jackson, in his book *How Lifeworlds Works, The Ambiguity of Being* (2013), argues that storytelling plays a crucial role in shaping our perceptions of life and how it constructs our identities.

> When we tell stories about our lives, we often focus on a single defining episode, as if the meaning of our life came into focus at that particular moment, sealing our fate. Undergoing initiation, crossing dangerous seas in search of a better life, losing a loved one, giving birth to a child, suffering life-threatening illness, living through war, surviving a natural disaster, or falling in love may all mark such limit situations. (Jackson 2013, 3)

The significance of how people share stories of particular life events is highly relevant because disability shapes and marks both one's social- and personal identity, and we all have multiple identities that are constantly changing and evolving. Identities are not static but are dynamically flowing back and forth in flux and alternate in social contexts (Kang & Bodenhausen, 551ff). The stories narrated by Jonas, David, and Karl all indicate that the body is being perceived differently by different actors in society. The concept of identity is thus complex, encompassing not only our inner thoughts and how we relate to ourselves but also our verbal expression and bodily actions play a big part in how we are defined (Jackson 2017, 8ff). Subjects develop their experience of existence through their interactions with and perceptions of the world. This includes not only relating to body-like and like-minded individuals but also "the dynamic tension that exists in all human relationships between affective and cognitive, or emotional and social imperatives" (Jackson 2017, 130). Considering the diverse and complex theory of life, what happens when an individual cannot adjust their bodily actions in various situations due to limited mobility? Given that identity and the conception of one's lifeworld are interrelated and intersubjective, and one's agency is rooted in one's mobility? (Csordas 2011, 147).

David, a man in his late fifties whom I met at his workplace suffered a brain hemorrhage a couple of years ago that causes him to spend the remaining of his life in a wheelchair. He had just guided me through and shown me around his workplace where he works voluntarily. He led me to the kitchen and asked me if I wanted a cup of coffee. He then led me to a lounge area and asked me to sit down as he moved his wheelchair, so he faced me on the other side of the table. As I sat in front of him and started my audio recorder, he started to talk. I noticed how much emotional weight he was carrying after the major life event he experienced, and he told me that his life drastically changed after he became physically impaired, especially since people who once used to be close to him gradually decreased their attempts to make time and get in touch with him.

> I used to have a lot of friends when I was well, but everyone has basically disappeared after I had my stroke. Well, I have a few friends left but (..) I am not considered interesting anymore when I cannot do "this" and "that" and give someone a ride here and there, and those kinds of things. So, that is awfully sad, really sad.

As our conversation progressed, David revealed that his family and old friends no longer bother reaching him to ask for anything as simple as a cup of coffee. When I asked him how he felt about it and if he had thought about why that was, he said he believed it was because they did not know how to handle him being different and how to treat him. He thinks they believe it is more convenient not to contact him since having him along would be difficult. As we sat together, sipping on our black coffees, I could not help but notice how David often referred to himself as "sick" while initiating and sharing new stories. Phrases like "When I got sick" and "Since I got sick" made me wonder if he truly considers himself sick, considering the social stigma regarding sickness and its associated consequences. As Mol argues, and previously discussed, medical conditions are not solely medical conditions, but also socially constructed ones that are being shaped and judged by cultural attitudes (Mol 2003, 147).

In medical sociology, the "sick role" is a functionalist theory introduced by Talcott Parsons in 1956 that claims that those who are ill have certain privileges over others, such as not having to live up to social obligations and expectations (Mccaw and Serva 2023). On the contrary, I argue that it is not a privilege not to meet social expectations, since it is impossible for those who suffer from permanent conditions to meet the obligations of society, even if they would want to. People who, despite being said to have certain benefits such as not being required to work full-time, experience social consequences of their medical condition. Since David is unable to meet

societal expectations even if he wishes to, it further highlights the ableist attitudes of society by implying that they have the advantage of having a "sick role" that benefits them in many ways. To further emphasize this, the story of Karl who suffered a stroke, said that it was particularly sad since his previous job included heavy physical labor, which he enjoyed very much. For him, it is not a privilege to have the "sick role" but a disability itself. David's experience of being abandoned by friends and family, a common occurrence among those facing chronic illness (Hartwell-Walker, 2016), may stem from the perception of having "the sick role" and holding certain social privileges, that others do not possess. The body and how it is being identified by others in social contexts overlap and intersect with one's identity and conception of oneself, depending on how one is socially identified in a cultural and social situation. This stresses the importance of one's body and one's agency as posited by Csordas (2011) concerning intersubjective relationships (Jackson 2018) and how they connect and interplay.

4.2 Intersubjective Relationships and Identity Shaping

When we experience major life events, whether positive or negative, we undergo transformative processes that change us and who we are and used to have been (Haslam et al. 2021). We reconstruct, redefine, and start to see ourselves from a different introspective lens, reshaping and overlapping our identity with a new one according to our new physical or mental form. Although we attribute new ways of seeing ourselves, we are also influenced by external factors, such as how we are being perceived and how we negotiate with the social world. Considering how people in Sweden have historically been treated, as discussed in chapter 3, how do such genealogies and historical events shape how people with impairments identify and perceive themselves?

Jonas, who was born with cerebral palsy has lived with physical impairments throughout his life and has always been physically impaired and been identified as such. Even though it has gradually become worse for him over the years, he was born with a mobility-restricted condition, in comparison to Karl and David, who suddenly became impaired due to a stroke and had to re-adjust and re-calibrate and enter an unfamiliar world full of new challenges. Learning from scratch how to navigate and to do the most apparently basic things, such as visiting the bathroom and going up in the morning. This made me curious about what it is like to sit in a wheelchair and how it affects one's identity, particularly for individuals like David, who got his condition later in life. I asked David to share his thoughts and try to explain to someone who is not in a wheelchair what it is like to be in his position. He made a brief pause, looking like he was figuring out how to answer that question. He

then said that it is impossible to explain how it is and that one has to experience it themselves. To understand how difficult it is, he said, one has to take the route from the railway crossing down to Uppsala city center to understand just how exhausting it is, especially when it comes to the pain that derives from bouncing up and down because of uneven pathways or cobblestone streets. When I talked to Jonas, he did not tell me so much about the physical constraints, but about the societal attitudes towards disability. When sharing their stories of social and environmental barriers, it became apparent that there were differences between being born with impairments and developing disabilities later in life. Additionally, there are various perspectives on how one views oneself and perceives the world. According to Jackson (2017), members of society often relate to each other unconsciously through an interrelated and intersubjective network of emotions. However, people tend to interact and form connections with those who are similar to them and with whom they share a mutual understanding (Jackson 2017, 130). When a body is considered deviant, the intersubjective and reciprocal understanding fades, as David's story implies.

This theory of intersubjectivity also suggests a bonding between people who share similar bodies and experiences (Jackson 2017, 8ff). This results in reciprocal understanding between subjects based on shared experiences and mutual intelligibility. In the cases of Jonas, Karl, and David, their condition only causes occasional fatigue and does not affect their cognitive abilities. Being part of a particular society is determined both by the physical body and cognitive abilities, as well as the exchange of thoughts and emotions between individuals (Cooper-White, 2010). Michel Foucault argued that agency is a social construct that is being "used" to regulate oneself to social norms and that "far from resisting the normalizing effects of power, they act to promote them" (Bevir 1999, 16). While promoting social order, we simultaneously reproduce and reinforce order and societal norms that influence our self-conception and understanding of the world. As agents, we can make use of the resources that society gives us (ibid. 1999, 18). The body plays a significant role in identifying subjects, particularly those who are impaired and use wheelchairs, deviating from other body types. This reveals that bodies, whether what clothes they are dressed in, or equivalent symbols, such as a wheelchair, become their social skins, as Terrance Turner (2012, 486) would argue. This becomes a visual representation of a specific type of person. The body then becomes a product of social relations and is therefore constructed within social contexts (McDonald & Lambert 2009, 5ff).

5. The Fallacy and Dissonance of Inclusivity

5.1 The Ambiguity of Modernization

Uppsala municipality has set a goal of ensuring that every resident feels included and can actively participate in society, acknowledging that several barriers prevent people with disabilities from fully participating in society (Uppsala Kommun, n.d.). Despite these challenges, their official website states that their ambition is to make the city accessible to all residents, as well as all visitors.

David, whom I met at his workplace explained that the town does not make accessibility improvements because of the large costs involved, as well as the ignorance towards the disability community and voices. Even though the municipality has made efforts to involve all Uppsala residents, its efforts have often proven to be unsuccessful. David told me a story when he was invited to an inauguration at an upcoming facility to evaluate its suitability and accessibility for those with impairments. When he began the story, he looked at me as if he had given up due to the municipality's incompetence to fix the most basic of personal needs. He said that the center's main attraction was superb, but if one was using a wheelchair and had to go to the toilet, it was impossible to close the toilet door because of the size of the room. Here, as stressed earlier in chapter 3 with support from Devlieger's (2023) theory, it is the hard infrastructure that is the issue, and not the size of his wheelchair that David points out adequately. After a brief pause, he told me a second story about how the municipality worked to improve accessibility by constructing wheelchair ramps on new buildings. He initially felt that it was a brilliant idea. The problem, however, was that the wheelchair ramp did not support electrical wheelchairs because of its narrow width and steep inclination. He stated that, based on his own experience before using a wheelchair and from others, those who need assisted walkers would most likely struggle to ascend that ramp. So how would someone with an electrical wheelchair be able to get up there? The problem, according to David, is that people without disabilities do not realize the seemingly small, but crucial details. And that also comes down to money, and not solely by ignorance.

David: Those unaffected rarely realize that these kinds of problems must be resolved accordingly.
Rasmus: Do you think the municipality of Uppsala is aware of the issues concerning accessibility for those who need it?
David: Absolutely. But it comes down to money.

Karl, whom I met earlier, told me that his condition has impacted his life greatly, especially since he used to be active and work in a setting where heavy physical labor was involved. Again, this once again renders the importance of one's mobility to exert one's agency (Csordas 2011). During our conversation, Karl expressed his frustration with the municipality's inadequate support and failure to resolve accessibility adjustments, such as curb cuts on pavements and non-functioning buttons on automatically opening doors, which he often requests to be fixed, but is often neglected by the municipality. When I asked Karl why he believed his requests were being neglected, he told me that he believed the municipality and people in general consider them unimportant.

> A lot of people think it is unnecessary and do not give a shit. The first time I drove longer with this [clapping on the armrest of the electric wheelchair] it all went fine until I had to cross a street. It was impossible to cross the street since the curbside was to levitate, and there was no curb cut. If I had tried to get down, I would've risked being stuck and hanging in this chair. So, I had to take another route and drive on the other side, which was not permitted. But it was my only choice since the road was wider on that side.

Karl's experience highlights the essence and the inadequate infrastructural planning, and the ambiguity that follows the municipality's goal, which is to achieve modernization on infrastructural, economic, and environmental levels, as well as factors of inclusivity such as accessibility for all. One cannot help but ponder that to achieve modernization, there must be a vision of what modernization is and what contemporary issues have to be fixed and improved for a society to be at the forefront of modernity. In my exploration of the Uppsala municipality's website, I found amongst the various visions from both 2022 and 2023 that one of their goals for 2023 is to "Welcome and include" and that "Every participant in society should be offered an environment where they can grow, develop, and have good health regardless of individual prior-conditions" (Uppsala 2003). Pondering that quote makes me wonder whether the lack of representation of people with disabilities on the board or in the decision-making process is hindering the municipality's ability to resolve accessibility issues. A group of "able-bodied" people have been tasked with developing accessibility adjustments for people with disabilities. As Jonas told me, the Uppsala congress-house got turned down by a commissioner on forty different accessibility criteria points because they did not include the perspectives of those who were to utilize them, so they had to start over and resolve it. There seems to be a double bias and cultural dissonance in such a case as people without disabilities make up plans on how to resolve an issue for people who have disabilities. By doing this, they are overlooking the insights of

those who are in need and making plans and judgments based on their own experiences and viewpoints, without considering the opinions and needs of the people who may eventually use these buildings.

5.2 Deceptive Designs

David's story about impractical and malfunctioning ramps raises questions about why those ramps only meet the minimum standards and are suitable for a certain type of wheelchair. For instance, the ramps David was discussing are suitable for lightweight and narrow wheelchairs that are 42-45 cm wide and used by small children or people with temporary impairments. This begs the question of why ramps are not more accessible and suited to a wider range of wheelchair users. American ethnologist Cassandra Hartblay (2017) wrote an article on wheelchair ramps in the city of Petrozavodsk in Russia. Hartblay argues that accessible infrastructure, such as ramps, is embedded in moral relationships and rarely works (ibid., 2017, 9). She argues that accessibility adjustments are "checkmarks" of the moral obligations of the state (ibid.) and gives an ethnographic example from one informant for her study, that shows how someone who is in a wheelchair can impossibly ascend the newly installed ramps, because of the ramps width (ibid., 2017, 2). This articulates the social stigma that arises when someone does not fit into the societal bodily framework, whether it is in Petrozavodsk in Russia or Uppsala in Sweden. Moreover, when a person fails to use a ramp that is designed to provide easy access, it creates frustration and underlines their difference from abled-bodied individuals, and people with disabilities are often seen as different from the norm and tend to face social devaluation as a result of this perception (Devlieger 2023). Since bodily actions are performative, they reinforce the already existing stigma associated with being disabled and the difficulties of navigating environments.

The municipality's plan to promote inclusivity has raised questions after reading Hartblay's (2017) article. It is suggested that if the municipality had consulted those who will utilize accessibility adjustments, the issues could have been addressed earlier, saving the municipality from spending more money afterward. By aligning the municipality's vision with lived experiences and opinions, issues regarding accessibility and inclusivity could have been solved. However, there is a clear dilemma, the municipality is aware of the issues but cannot solve them due to a tight budget and limited funds. Despite this, they can start projects with the goal of inclusivity and strive to meet the required standard. However, not everyone can access buildings that only meet the bare minimum of accessibility standards, since not every impaired body is the same, and not every wheelchair is alike.

It seems that the state is using its authority to control building access based on preferred specific types of bodies. Depending on the type of person, the apparently simple act of visiting places like concert halls, town squares, sports events, etc. may reveal something about that place, and the characteristics of the people who frequently visit them. The municipality's repeated failure to make adequate accessibility adjustments, which only barely meet the bare minimum, suggests that they are fulfilling their "moral obligations," as Hartblay argues, but not taking those who are affected experiences and voices into consideration.

6. Conclusion

The narratives presented by Jonas, Karl, and David revealed multiple discrepancies in societal and material structures that are not aligned with the municipality's visions for inclusivity and equal terms for all participants of society. However, the responsibilities for these issues cannot solely be blamed on the municipality, but the social structure concerning normativity adjacent to ableism from both a historical perspective and systematic mistreatment of different-abled bodies and minds, like those at Beckomberga in the mid-1900s and the societal and normal standard as of today. Considering the walk-and-talk with Jonas, it becomes evident that ableist attitudes and bodies dominated the town square of Uppsala, making it challenging for Jonas to be comfortable on the streets and in stores, and to express his agency as he wishes. Karl's encounter with the police, who he believed thought he belonged to a home for dementia patients, as well as the "sick role" theory further emphasizes the social construction of bodies that may not be aligned and does not correspond with the participants experiences of their condition. The causes for these situations are many, but we can certainly see connections between material and immaterial interplay, such as environmental obstacles and societal attitudes, which I would argue both areas affect and influence both factors.

Despite the differences in their stories of discrimination, their shared stories and strive for inclusivity take on a significant meaning that becomes a phenomenon, with the wheelchair functioning as the connecting element that mediates how their bodies are represented. The phenomenon and lived experience of sitting in a wheelchair and existing in different able-body according to the interlocutors, whether innate or not, has demonstrated itself to be primarily a societal challenge, rather than a physical one. While telling stories about how their mobility impairments cause discomfort while navigating public areas, examining the value of the physical body in its cultural contexts, as well as its confrontation with social stigmatization while traversing through an ableist environment has shown to be an everyday hassle, which is being reproduced and reinforced through infrastructural designs and processes. Jonas, David, and Karl all share stories of discrimination and how it affects them daily, highlighting ableism as a structural issue that exists at multiple levels and beyond the physical barriers. Apart from struggling to navigate in the physical environment, one also faces the social barriers of being disabled and is always looked at and judged from an ableist perspective, where society and the municipality fail to understand the intricate challenges people with disabilities face every day.

References

Allen, Charlotte (1997). Spies Like Us: When Sociologists Deceive Their Subjects. *Lingua Franca* 9(7), 31-39.

Barker, Chris (2005). Cultural Studies: *Theory and Practice*. London: Sage.

Calvey, David (2008). The Art and Politics of Covert Research: Doing 'Situated Ethics' in the Field. *Sociology* 5(42), 905-918.

Crapanzano, Vincent (2003). *Imaginative horizons, an essay in literary-philosophical anthropology*. Chicago, University Press.

Csordas, Thomas. (2011). Cultural Phenomenology. Embodiment, Agency, Sexual Differences, and Illness. In: *A Companion to the Anthropology of the Body and Embodiment, First Edition.* 137-156. ed. Frances E. Mascia-Lees. Blackwell Publishing.

Devlieger, Clara (2023) 2018. Disability. In *The Open Encyclopedia of Anthropology*, edited by Felix Stein. Facsimile of the first edition in *The Cambridge Encyclopedia of Anthropology*. https://www.anthroencyclopedia.com/entry/disability

Durban, L. Erin (2021). Anthropology and Ableism. *American Anthropologist* 124(3), 1-15.

Fleischer, Doris and Freida Zames. 2001. *The Disability Rights Movement: From Charity to Confrontation*. Philadelphia: Temple University Press.

Foucault, Michel. 1982. The Subject and Power. *Chicago Journals. Critical Inquiry* 8(4), 777-795.

Geertz, Clifford (1993). Religion as a cultural system. In *The interpretation of cultures, selected essays*. 87-125. Fontana Press.

Hartblay, Cassandra (2017). Good ramps, bad ramps. Centralized design standards, and disability access in urban Russian infrastructure. *American Ethnologist. Journal of the American Ethnological Society* 44(1), 9-22.

Hartwell-Walker, Marie (2016). Why Friends Disappear When Crisis Turn Chronic. *Psychcentral.* Accessed: 2023-12-06. https://psychcentral.com/lib/why-friends-disappear-when-crisis-turns-chronic#1

Howell, Signe (2018). Ethnography. In *The Open Encyclopedia of Anthropology*, edited by Felix Stein. Facsimile of the first edition in *The Cambridge Encyclopedia of Anthropology*. Online, http,//doi.org/10.29164/18ethno

Hsieh, Hsiu-Fang and Sarah Shannon (2005). Three approaches to qualitative content analysis. *Qualitative Health Research* 15(9), 1277–1288.

Huxley, Margo and Andy Inch (2020). Urban Planning. *International Encyclopedia of Human Geography*. https//www.sciencedirect.com/topics/social-sciences/urban-planning

Jackson, Michael (1977). *The Kuranko, dimensions of social reality in a West African society.* London, Hurst.

Jackson, Michael (2018). *How Lifeworlds Work. Ambiguity, Sociality & The Ambiguity of Being*. The University of Chicago Press.

Kang, Sonia K and Galen Bodenhausen (2015). Multiple Identities in Social Perception and Interaction, Challenges and Opportunities. *Annual Review of Psychology* 66, 547–574.

Karlsson, Leena and Jamie Bolling (2022). Friheten att bestämma med vem, var och hur en vill bo – Avinstitutionalisering/Deinstitutionalisering (DI) I Sverige. *Independent Living Institute.* https://www.independentliving.org/files/AvinstitutionaliseringSverige.pdf

Krug, Henning; Alexander, Haslam; Otto, Kathleen and Steffens, Niklas, K (2021). Social identity makes group-based social connection possible: Implications for loneliness and mental health. *Current Opinion in Psychology* 43, 161-165.

Lambert, Helen and Maryon McDonald (2009). *Social bodies*. New York, Berghahn Books.

Mccaw, Pat and Christine Serva (2023). The Sick Role Theory. *Intro to Sociology Syllabus Resource & Lessons Plan.* Accessed: 2023-12-06. https://study.com/academy/lesson/sick-role-theory-in-sociology-definition-lesson-quiz.html

Mol, Annemarie (2003). *The Body Multiple, Ontology in Medical Practice.* Duke University Press.

Pink, Sarah and Jennie Morgan (2013). Short-term ethnography, intense routes to knowing. *Symbolic Interaction* 36(3), 351–361.

Pranka, Maruta (2020). The walk-and-talk methodology – researching place and people. *International Interdisciplinary Scientific Conference* 85(7), 1-7.

Ruby Reid-Cunningham, Allison (2009). *Anthropological Theories of Disability. School of Social Welfare*. University of California. https,//web.mnstate.edu/robertsb/306/Anthropological%20Theories%20of%20Disability.pdf

Turner, Terrance (1994). Bodies and anti-bodies, flesh and fetish in contemporary social theory. In, *Embodiment and Experience, The existential ground of culture and self*. Ed. Thomas, Csordas. Cambridge: Cambridge University Press.

Turner, Terrance (2012). The Social Skin. *HAU: Journal of Ethnographic Theory* 2(2), 486–504.

Uppsala Kommun (2022). *Uppsala Kommun inriktningsmål till och med 2022*. Accessed: 2023-11-25. https://www.uppsala.se/kommun-och-politik/kommunens-mal-och-budget/mal-och-budget/inriktningsmal/

Uppsala Kommun [no date]. Fokusmål 4. *Uppsala ska bli tryggare med jämlika livsvillkor. Trygghet och jämlikheten*. Accessed: 2023-11-25. https://www.uppsala.se/kommun-och-politik/kommunens- mal-och-budget/mal-och-budget/fokusmal/4.-uppsala-ska-bli-tryggare-med-jamlika-livsvillkor/

Zigon, Jarrett and Jason Throop (2021) 2023. Phenomenology. In *The Open Encyclopedia of Anthropology*, edited by Felix Stein. Facsimile of the first edition in *The Cambridge Encyclopedia of Anthropology*. Accessed: 2023-11-25.
http,//doi.org/10.29164/21phenomenology

Øyen, Simen Andersen and Birger Solheim (2015). *Akademiskt skrivande, en handledning.* First Edition, Malmö, Gleerups Utbildning.