BECOMING DISABLED: KNOWLEDGE AND TRUTH

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Introduction

> “Major politics is based on defined and stable identities, and on a definite, enclosed social space. ... Minor politics allows for identities themselves to be challenged, for definitions to be shattered, for power relations to be fundamentally undermined (by undermining the factors – identities, definitions – that enable the exercise of power in the first place). … [Minor politics] rushes to the fringes, toward the marginal, minor characters who populate them, and who repeatedly bring about becomings that unceasingly unravel and reweave the social fabric.[i]

Am I disabled? This is the question I frequently open my lectures with. To this direct and unexpected question the audience usually reacts with tension, confusion, and uncertainty. They are meeting me for the first time and are surprised at the request and demand to decide about me for themselves and the opportunity they are given to respond honestly and bluntly. This dialogue is situated within specific power dynamics–

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between my position as lecturer and the position they hold as students. Responses flow and indicate to me the various ways in which each one of them read my body, attribute meaning to it, and, at times, give it a name. Some of their answers are more resolute, others less so. Still, the responses are always varied and develop into powerful and intense group discussions which indicate the multiplicity of possible interpretations and the lack of stability in the category of disability. It appears to me that these discussions have the potential to undermine disability as an essential and objective status. What remains at the end of these heated and unresolved sessions is a protruding dilemma: what, if there is such a thing, is disability?

For the purposes of this article I aim to re-arouse the doubts that are present in such discussions and linger on the moments of uncertainty that prevail in the processes of decision making on the surface of my body. The political philosophy of Gilles Deleuze and Félix Guattari[ii] will serve as a theoretical base through which I question, reflect on, and undermine 'disability' as an essential state of being.

It is important to note that Deleuze and Guattari critique the very act of attributing terms as one of control and determination that serves to create and imposes fixed boundaries. They criticize such naming as an action of power over. Therefore, I tread carefully acknowledging the danger and impossibility of representing in finite words a powerful philosophy that challenges and seeks to undermine the necessity of classification and categorization.

According to Deleuze and Guattari, the processes of identifying, quantifying, classifying and fixating, inherent elements of "major politics", serves to create a reality of binary distinctions. As an alternative they propose "minor politics" which serves to acknowledge and summon for a “thousand plateaus”[iii] for the purposes of untangling the hegemonic anchoring points which would allow movement between the multiple and changing realities. “Minor politics” is valued for its escape from the hegemonic binary structure by instead allowing for the exploration of multiple and diverse realities which flow without organization or fixed structures. Deleuze and Guattari suggest a critical element of “minoracy” is the ongoing process of as “becoming”, a dynamic evasion of classifications which comprises a performance of floating (without any identity) and moving (between fixed identities). It is through this process that one “becomes-minoritarian.”[iv] Minoracy unravels the concept of a fixed and classifiable identity.

In this paper I will focus on the concept of *knowledge* and will illustrate the ways in which diverse bodies of knowledge can produce me a different body; on the one hand, the concept of knowledge is derived from the “majoritarian model” which seeks to order categorize and label. On the other hand, this production of the body is a concept that connects to “minoracy” and relates to “becoming”, representing and symbolic of changes, movements and metamorphous.

Methodology

In order to explore and demonstrate the process of “becoming” with a specific emphasis on ‘becoming disabled’ I utilize my own critically reflexive experience. A qualitative autoethnographic method is employed.

Autoethnography is a qualitative research method that arose from the crisis of representation in the social sciences, specifically the critique of dominating positivist approaches by relativist theories, postmodernism and feminism. Qualitative approaches re-evaluated and re-defined as an act of interpretation; one that involves elements of power and selective story telling.[v] Accordingly, information that a researcher encounters became recognized as knowledge filtered through a subjective classification system that is personally and culturally situated. Autoethnography makes room for the researchers' presence and subjective voice, an expression of their personal experience of reality, as such is the corpus on which the research is based.[vi] Autoethnographic writing draws on and connects the personal and cultural, situating the self within its social frame.[vii] Within this framework the work of documentation is made transparent as an interpretative act, one that doesn't just describe reality but also mixes within it and becomes partners in its creation.[viii] An autoethnographic approach aims to enable those in the marginalized groups of society to speak and be heard in their own voices.[ix] In response to claims that autoethnography is emotional and narcissistic,[x] it is critical to note that this methodology calls for ongoing critical reflexivity and transparency of the researcher.

Through this paper my personal narrative will present the complexity and the tensions between majority and minoracy. Specifically, I will examine the dimensions of power laden within each label my body encounters. Additionally, I will penetrate the "lines of flight",[xi] movements that escapes labeling. Following, I will critically explore the notion of *truth* related to the label of disabled, particularly with regard to its urgency when encountering state proceeding.

Common Knowledge

I guess I was always the smallest girl in the house, the smallest in playgroup, the smallest in the class, and the smallest at recess. But that doesn't mean that I knew "it".

"It" didn't turn into self-knowledge. After all, what exactly is this "it" that I'm talking about when I declare that of "it" I did not know. "It", "this" - these are all concepts that obscure, inherently meaningless in and of themselves.

From my memories of early childhood my height during that time was inconsequential for me. Like other children, I explored the world and my body, and that experience was of singular value. I lived in the world and in this world there were things that were discovered as more permanent than others, certain things I could influence more than others, things that were more pleasant for me than others. When I could not reach something, the experience of asking someone else to lower it for me or of using my own strength to climb up and get it for myself, seemed equally logical to me in the same way that it is probably logical for other children who are unable to reach things that are high up. For “this”, which today I vaguely call "my height", was relatively meaningless and I never stopped to consider it in any special manner. – That is, until others around me related to it.

The question of what or who creates reality is pressing; is it the material body, which has certain characteristics and to which people respond, or is it possibly the reaction of others that becomes the active site and mechanism of knowledge construction and thus, reality?. In this paper I suggest that the answer to the question lies in the relationship between action and the body. Furthermore, the creative dynamics between action/reaction and the seemingly concrete material body are bidirectional and often inversed. For me, as long as there were no reactions, my "height" did not exist in my reality; my height was nonexistent before children stared and commented on it or before adults stared, and then quickly averted their eyes in order to make it appear as if they were not looking.

Rosemary Garland-Thomson[xii] examines the emerging need in human beings to stare at others whose bodies are deviant from the normative standard. Immediate, almost intuitive, attention draws the gaze to an unexpected body. A person is stimulated to gaze at the wonder open before him, to investigate, to record its unique characteristics, and hope to find a satisfactory answer or excuse. Despite this expected and almost presumed instigation to look, in American society, adds Garland-Thomson, the person is expected to avoid making eye contact with the other. The moral requirement not to look creates a game of secret staring and the diversion of the gaze to the side as soon as it is detected.

The full range of reactions that are enacted toward me in the public sphere make it clear to me that there is something that is different, something that is other, that my body is something that needs investigation and justification. This is not knowledge that grew from within me; rather this is knowledge that is foreign to me, knowledge that is transmitted to me from the outside, through interactions and reactions of others towards me. This is knowledge that is not known to me despite its intimate relevance. It is knowledge *on* me. These reactions don't remain stagnant or solely in the position of reaction; rather they produce meaning and bring about a chain of meaningful actions.

My encounter with myself as extraordinary is not intimate; it is an interaction through mediation that produces a partition within me. According to Frantz Fanon[xiii] this partition turns into recognition of the body in the "third-person." According to Fanon, the gaze constitutes a powerful element, tarnishing the skin, making it black and designing the body as primitive and animal-like. The external gaze teaches the observed subject of their body's differences, loading it with stigma, estranging it from themselves.

When I seek to know my body, to be a spokesperson for it to myself and to others, it becomes unclear, even to me. This is the process I experience, the process of knowing my own body in a "third person"; the process that makes me "little". Garland-Thomson[xiv] discusses the dynamics of "Stare-and-Tell" – the experience of a person with a deviant body who goes into the public sphere, and becomes the recipient of stares and questions that demand from him to justify himself, to give language to that which is physically revealed to the spectator. I learned about myself through the others, through their stares and questions that were directed from outside, questions to which I did not have a response because for me the questions did not exist prior.

"Are you a mother or a girl?" This I did know. I am not a mother, nor am I a girl. "It's a doll? Touch it!" No one touched me, I am not a doll. "Why is she little?" My degree of difficulty increased considerably. Why am I little? These questions penetrated me, pounding through my eardrums, pulling my personal body out of my hands. "Joint disease", "genetics", "mutation", becomes referents which minimize me to a medical problem. These are the explanations issued to me by the same culture that created the need for these question, a need that did not exist prior and did not have to exist, and answers that could have been different. A child to whom I responded with the "heredity" answer, the answer that was most concrete and logical, came back to me again with the same question: "why are you little?" The answers I gave will never be satisfactory, not even for me. But, I felt at the time, and still do to a certain extent, that these were the only acceptable answers I had to give.

During my life many such inquisitive stares were directed to me, questions that I did not have were posed and answers I did not know were demanded; I was expected to engage in an ongoing investigation posited on me by others. This created a gap. On the one hand these inquisitions indicated the social expectation that I know myself and am able to explain who I am to others, namely to justify my body and explain "why?". This is a place where I am perceived as the source of knowledge. On the other hand my reality is that I often do not know and certainly cannot articulate and justify my own body. The manner in which I attempted to answer the children, namely through medical discourse, knowledge that I also obtained externally – was not successful. This knowledge on heredity was revealed partially, insufficiently, and essentially left large question marks. A satisfactory response was not given, not to me and not to those children that turned to me and asked me "why?"

The public space that I described until now was the site which revealed me to myself with the label of "little". Little is a label the children placed on me and is a label that I want to place within the category of "common knowledge". I utilize the term "common knowledge" to refer to knowledge that is commonly and socially seen as clear and self-evident, ontological, and as truth. The label of "little" that was given to me by children was perceived as a concrete descriptor of reality and nothing else.

However, the new definition of me as "little" cannot be understood as stable and clear cut. The label itself and the explanation that followed did not erase the question mark not for the children and certainly not for me. On the contrary – it created the question and enhanced tensions.

The situated label of little contains within it contradiction and puzzlement of the overlapping opposites of little and adult. My body served to deconstruct elements of the social world by threatening the fundamental and socially necessary distinction of grownup versus child. In Deleuze and Guattari's theory this drift toward uncertainty is what they call "becoming-minoritarian."[xv] Becoming minoritarian does not place me in a fixed identity; it escaping identity and undermining definitions. As is evident in my experience, there was a lot of mystery involved in my process of becoming little. The question of "why?" dominated the encounters between myself and others, and consequently between me and my body. It continued to echo; unresolved.

Professional Knowledge

The medical system is the primary means whereby western society is expected to learn about and know the human body. This system has merited almost exclusively the right to dissect the body that is deviant and unexpected, the body that culturally is seen as something that should never have existed, the body that arouses social anxiety, the disabled body.

Susan Wendell explains that "medicine has both the cognitive and the social authority to describe our bodies"; [xvi] medical professionals' communicate with the human body and are authorized to give it language, meaning, interpretation, definitions and boundaries. Such communication with the body is established through what Michel Foucault[xvii] called the "clinical gaze". While in the public sphere people are expected not to fixate their gazes on unusual bodies, the medical profession is bestowed with the unique privilege of prolonged gazing and observation. Foucault claimed that the development of medical science was dependant in the clinical gaze; constructed and understood as pure and objective, one that the body conveys to it its true essence. The discipline of medicine is based on the focus of the gaze on the body, on the enhancement and improvement through observing the body and penetrating gazes that transfer far beyond the boundaries of the skin. Human pathology allegedly exposes itself in front of the clinical gaze and a system of notation that justifies the classification and categorization between people. Medical knowledge is established through this professional exterior gaze on the materiel body and becomes articulated by Wendell as a "vocabulary of third-person."[xviii] This term seems to resonate with Fanon's notion of recognition of the self in a third-person. The language that construct the deviant body is relies on the outer observer. Wendell argues that this language often exclude or distort patients' experience and misses the aspects that are most important to them.

Medical discourse that attempts to create for me a body that is deficient and lacking is in itself lacking knowledge. "You are walking well", reports the orthopedist, "Why are you using a wheelchair? You give up on yourself too easily." I suffer from pain. Because of this there are times that I use a wheelchair. I am now in a room without my wheelchair. I am sitting on a chair that I found in the room and am describing to him my wheelchair use.

I get up from the chair and leave the room to go to the x-ray room. There I lie down on a cold metal surface with my pants rolled down. For a few minutes I am left alone in the room, freezing in the uncomfortable position that I was asked to stay in. I return to the orthopedist with a pelvic x-ray. He looks at the x-ray that is exposing my body, my insides, my intimate. Through the photo he gets to know me. Through him I get to know myself. “You have no joints.” I am trying to absorb, repeating to myself his words: he said that the bones of my pelvis have no joints. I look at the x-ray, trying to see the absence. Neither the skeletal system I am familiar with from popular science programs nor the model of the pelvis sitting on the table of the doctors’ office, are similar to the skeleton in the x-ray. In this photo I look distorted; a grotesque and monstrous skeleton is hidden within me. I try to clarify with him which joint is worse. “Left. No, actually right. Neither of them are good.” He asks to show the x-ray to an orthopedic colleague of his. I nod. He takes my pelvis and walks out of the room with it. He enters into the next room. They are speaking. Laughing. He returns to the room that I am in, all smiles. He throws out that “he” – the second doctor – “didn’t pass the test.” I don’t understand what the questions for the test were. He returns the x-ray to me. “Will you agree to write a medical opinion to the committee determining my mobility?” I am trying to get a professional reference stating that I need a wheelchair. “You don’t need a letter. Simply let them see your x-ray.” I tell him thank you and I leave. I walk by foot to the car. I'm hurting. I am feeling the no-joint on my right side.

In this narrative there is the space of the "no" and the “no-joint.” These characterizations turn me into someone who is lacking. In essence, my body becomes a site of absence, of lack, of something that doesn’t exist, something that should have been but in actually is not there. A similar construction of lack can also be seen in the semantics of the term “dis-ability”.

Simi Linton[xix] talks about the various meanings of the prefix “dis” such as not, absence, opposite, and deprived. She elaborates and explains that the dis “creates a barrier, cleaving in two ability and its absence, its opposite. Disability is the 'not' condition, the repudiation of ability."[xx]

In the orthopedist room I am defined and categorized based on what I don't have rather than what I do have. The same thing that should have been but is absent is turned into something that defines me, my essence. Returning back to the concepts of knowledge, I question how it is that knowledge can be considered based on the "no" or the "dis". How is it that medical knowledge successfully tell me about myself when its' data is based in and through the negative of what I am not?

In the doctors examination rooms I am not perceived as acknowledgeable authority. My statements of what I am experiencing in my body are largely disqualified or ignored. In contrast to the previous space where I was interacting with the young children and it was expected of me to be the owner of knowledge and to provide answers, in the orthopedist room the underlying assumption is that the professional who does not live my life is the bearer of knowledge and can tell me and others what I am, who I am, what I experience, what my chances are, and how something will affect me. The professional is turned into the authoritative source of knowledge about my body. Assuming he is aware of all relevant considerations, the physician criticizes and denies my legitimacy of selecting and making use of a wheelchair and he assumes it would be right to choose a different way, a more normative one. For him only the x-ray of my pelvis verified my need and gave a rational justification for my use of a wheelchair.

Wendell[xxi] criticizes the silencing of the knowledge of people with disabilities by healthcare professionals who are seeking evidence with objective validity. In situations such as the one described above, interactions that are characteristic of the medical system, my testimony of pain is insufficient until the orthopedist sees the x-ray and receives confirmation of my claim, only then and only through the clinical gaze, is my experience validated.

Medical labels are powerful in that they cross spaces and turn into formal knowledge. Since a medical label has professional status its influence is significantly different from labels that are encountered and enacted in everyday life. Medical labeling does not remain fixed in the immediate context of the direct encounter with the medical professionals, rather it is written in paper, signed, and sealed. Signed medical documents are transferred into personal files; they are saved, preserved, and distributed. The writing in and of itself is a way of institutionalizing the medical label and turning it into reality.

According to Deleuze and Guattari's, medical knowledge can be identified as majoritarian. The label invented by medical professionals is officially and permanently attached to my body, at least that is the intent. The medical label is not thrown into the air and concretized in a specific time; rather, it is recorded and preserved together with the knowledge that is socially constructed in the medical field. When professionals want to know about me, they return to the same files that were written about me by their colleagues, to a label that refers to the data of medical facts and research that don't necessarily speak to or about me – on my specific case – rather have become part of the knowledge on me. The same medically documented labels are utilized to categorize me and situate me within a wider pool of knowledge. This is a scientific knowledge that is represented as objective and empirical, one that only a critical lens can deconstruct and identify it as an interpretation and political.

This professional knowledge and language that defines and categorizes me is also not accessible or understandable to me, its very object. If in the previous space, I wore the label of “little”, I have now moved to a different label, that of “Multiple Congenital Epiphyseal Dysplasia.” This name was constructed from a number of Latin words that are unfamiliar to me. This is the label that is included in the medical documentation. It is a label that I do not use in my day to day life. The medical label includes within it prior knowledge that I am unaware of, knowledge that is geared towards professionals and is not necessarily available to the people like me, who live it themselves. This label is much more stigmatizing and powerful than the previous one. It is loaded with an ideology that prefers normalcy and contains value judgments that position me and my body, as inferior and problematic. This label is also often legitimizes intrusive treatment and surgical practices.

First-Person Knowledge

The following knowledge space that I seek to address is first-person knowledge – knowledge that a person experience, knowledge that he formulates himself throughout his life. Specifically, I will focus on experiences of pain.

Elaine Scarry[xxii] argues that in the moment of pain a person separates from the universe around him and creates a split between himself and others. He experiences his pain and his body and is conscious of it in a certain manner. It is an experience that the people around him do not enter, recognize, or experience. In such a moment a barrier is created between the person in pain and others. Scarry speaks about the uncertainty others experience when a person says “I am in pain.” People who hear this are unsure what it means and the ways in which the person is experiencing the pain. Returning to the encounter with professionals, I reflect on the moment that pain entered the situation and my body became concealed and unreadable to the orthopedist. That was a moment where knowledge became closed off to him. The orthopedist had no agent aside from my declaration. He thus turned to an external confirmation (an x-ray) to testify to my claim of the existence of pain in my body.

In her theoretical work Scarry discusses the resistance of pain to language. Specifically she points out how pain is an elusive concept within common language. There are almost no words that can articulate pain or give it adequate testimony. The difficulty of expressing physical pain questions whether a 'vocabulary of first-person' can be achieved?

To me, the experience of pain is amorphous, abstract, and fluid. Even when I myself am experiencing it, it is extremely difficult to focus on pain and to make sense of it. I ask myself when does the pain appear? Where? What causes it? If I avoid such and such activities will the pain not show up? If I do all of these activities will that mean it will return? My personal experience says no. I do not hold a mathematic formula for pain that can be utilized in reality.

For me, pain is an elusive experience, one that is not disciplined to the commonly accepted map of the human body and biological systems that include separate body parts such as bones, nerves and muscles. The map of the human body is socially constructed based on narrow normative structures and neither deviant bodies nor the experience of pain subordinate to it. The experience of pain is one of making oneself a body without organs, claim Deleuze and Guattari call it. “Body without organs” is a term they borrowed from the poet Antonin Artaud. “This body without organs is permeated by unformed, unstable matters, by flows in all directions, by free intensities or nomadic singularities, by mad or transitory particles.”[xxiii]

During Paula exercises I am lying on my back. The therapist guides me to try and target the pain that I am experiencing in my body. I begin to imagine the pain, to draw it in my mind. I feel pain and imagine it as cold metal attached to my body, creating a different sensation of the flesh. In another place I experience pain like a thorn stuck in me, stabbing me in me in my joints. During this experience of pain and the attempt to define it, I notice that the experience itself is changing. What before felt like a thorn turned into something sharp and pressing. What was metal has turned into something more like ants crawling inside me. I find that the experience of pain is not absolutely certain to me. I can feel it, and change with it simultaneously. I do not know what was there and if what I imagined influenced the experience. I am starting to categorize one specific aspect of pain and then suddenly it disappears and dissolves into something else. Despite this, a place that I wasn’t feeling before suddenly rises to the surface and I become aware of it as a place that may be in pain. I note for myself that I have pain in my knee, and after a moment I still experience the same pain but not necessarily in my knee. My pain is shifting, changing places. I start to become aware that the pain from my knee is trickling down to the heel of my foot and that my knee hurts less.

Pain is fluid, it is spread out, and changes forms. The experience of pain is dynamic and changing.

There is a need to understand that it is difficult and maybe impossible to formulate knowledge about pain. The experience of pain is not stable or obvious, not even to the subject experiencing the pain, and it is not clear if the experience is able to be translated into language and knowledge. In the ambiguity surrounding the body, the experience of consolidating knowledge about the body becomes something extremely complex. In claiming ownership of the knowledge of pain, perhaps we may be left with the negligible argument that pain is hazy and variable.

This subjective knowledge space cannot contain any fixed label. I could have written that first person knowledge puts me in the role of “the one in pain”. But to such a label appears imprecise and problematic, a label that misses the point, one that dismiss the thousand plateaus. Instead I adopt the elusive description of “becoming.” This is not of internal essence I possess as identifiable being but a flexible, contingent and changing existence. If the doctor wanted to define my body as one that is “not”, here there is the experience of “is”. My body becomes something present, felt, a living body. My body is no longer the visible body that is externally defined for me by strangers or by doctors, here I experience my living body and sometimes I cannot avoid experiencing it, even if I want to.

First person knowledge to a large extent deconstructs the ways in which knowledge is commonly understood. Inspired by the concept of minoracy developed by Deleuze and Guattari, I would like to make a hybrid concept and call the first-person knowledge 'minor knowledge.' Through the pain, the limited capacity to know the body, to observe it, and to case it into linguistic or consist meaning, is revealed. It appears to me that corporeal experiences enable the development of knowledge that is transient, singular and unique, unable to be quantified, reproduced, or translated into social policy. This is fragmented knowledge, difficult to solidify or fix, yet always felt.

Searching for the Truth

The medical committee is a powerful majoritarian decision-making institution established by the government of Israel and operated by the National Insurance Institute. It is a framework of bureaucracy that was created in order to set material boundaries that have a profound and concrete effect (financial and others) on reality. The boundaries they set are also symbolic as they construct and concretize categories of difference and otherness, worthiness and lacking. The criterion that the medical committee establishes creates and determines seemingly concrete social categories of "disabled" or "not disabled", presumed to be fixed and opposing identities. Acting as the gatekeepers of the governmental wallet, the medical committee establishes the binary categories of disabled vs. not disabled and turns it into a spectrum of eligible vs. not eligible, disabled enough (to merit benefits) or not. Only those who are recognized as sufficiently disabled by the state (based on professional assessment through quantifiable and verifiable measures) are able to enter into the eligible section of the spectrum.

There are complex dynamics at play in these medical committees that are situated within medical science and its assumptions of power, knowledge and truth. There is a cultural assumption that medical science and thus by extension medical professionals, are sincerely motivated and strive to discover essential truth and reality. However, in the medical committees there is a gap and tension between the theory and practice of truth. On the one hand the authority of medicine enables the medical committee to continue to be perceived as a structure that investigates and promotes truth and truthful results which have value in and of themselves. On the other hand the underlying but protruding premise of the medical committee is that what exists is deception and that truth is an unstable category in the interplay during the committee.

The first medical committee that I remember going through was one I went to when I was a young girl. My older brother was with me and was also being evaluated for eligibility. With greater understanding of the mechanisms of operation of these committees my brother taught me that in these meetings there is a need to emphasize my difficulty with walking. He suggested that it would be desirable for me to tire myself out before the examination. On his recommendation before we stood before the committee, we started walking in the nearby courtyard. We walked in one and a half meter circles. We walked, one after the other. The ceremonious effort we made together far exceeded our regular behavior; in our daily lives we make great efforts to reduce the amount of walking we do to ensure we don't overdo it which increases our pain. During our walk in circles, a road with no destination, we started to laugh. This walk provided a sort of release from our strict daily demand from us to avoid unnecessary walking. Suddenly, in the alternative space that was created for the examination by the medical committee, the acquisition of pain became a legitimate and desirable goal.

In my daily life I have taught myself to self-police my body. I am careful to reduce my daily physical activities and not to walk too much, to limit my activity, to ensure that I do not exceed the minimal permitted amount, to stop before my body signals to me that I overdid it. For me walking has been a way to get to a destination in the shortest, and most comfortable, ways that will make me exert the least effort. All of these calculations are done in order to avoid and/or delay physical pain.

Preparing for the medical committee I was suddenly provided with a unique opportunity. In the moments before I entered this medical committee it was like I was given permission to walk, just for the sake of walking, and not for my usual direct purpose. It was as if someone was saying to me “go wild! Experience walking.” Before entering the medical committee I was suddenly liberated from my ever present “effort calculator” that is always working in my head. I was able to release it and “just walk.” It was a place of pleasure. I enjoyed the casual walk. For me, the situation contained elements of entertainment.

Tobin Siebers discusses “the ideology of ability” [xxiv] which translates into the social preference for standardized and normative able-bodiedness. He argue that this hegemonic ideology produces a hierarchy of humanness which operates on the premise of “[t]he lesser the ability, the lesser the human being.”[xxv] People with disabilities often are expected and attempt to minimize the presence of difference as much as possible, to give it as minimal visibility as possible, to attempt to pass and portray oneself as *more*, more worthy, more equal, and more of a human being. While passing in the classic sense of the term means concealing disability from discovery in attempt to obtain a legitimate identity that is culturally desirable, with masquerade the action is reversed and a disabled identity is represented. Siebers introduce masquerade of disability as exaggerating display of disability.[xxvi] Therefore my attempt to arouse physical pain and to perform in front of the medical committee as disabled can be understood as masquerade.

The medical committee invites this illegitimate social performance of disability and transforms it into something that is expected and even valued. Fixed interest in reducing the appearance of disability and constant calculations are suddenly pushed aside and the performance of disability is given space. The medical committees invited me to experience the role of disabled in a way that is more extreme, less acceptable, more threatening. Here is an almost once in a lifetime opportunity to put on a mask that I am really scared of in the day to day, and here to actually experience it. Suddenly I was allowed the opportunity to give unpleasantness disability expression and to bring it into the arena of human communication. In this regard, the medical committee is a unique and exclusive arena. This display was one I almost never allowed myself until then. It was a unique opportunity that I hope can move outside the medical examination room.

The preparation for the medical committee that consisted of walking in endless circles seeking to create the chronic pain that I experience and attempt to avoid in my daily life, played with and challenged the concept of truth. It can be said that in that preparation I attempted to create something that at the moment was not there, and that therefore those moments and those that followed in the committee were false and thus a deception. But with an understanding of the medical committee from the perspective of masquerade, the concept of truth becomes irrelevant. How much is it really possible to say that something is not true or less true than the day to day, when on a daily basis I relinquish walking and constantly calculating the amount of physical efforts I can exercise?

Masquerade refuses to obey the ideology of able-bodiedness and subvert existing social conventions. In his research Siebers discusses the strategic use of a wheelchair as a way to pass as disabled. In western culture a wheelchair takes on a great deal of symbolic significance as the ultimate symbol of disability,[xxvii] so it can be understood as the most straightforward and obvious masquerade of all.

For years I have been using a wheelchair as part of my daily life. I use it to prevent myself from experiencing pain during or afterwards. The wheelchair is used as a means of bypassing and deferring pain. I turn to it when I want to move around or need to prevent myself from having to stand for long periods. Sometimes when I am using the wheelchair I stand up and after a while I sit back down again. This variability can evoke responses in people who see me and question my need for a wheelchair. In the medical committee this dynamic is expressed in an extreme manner.

I chose to bring my wheelchair with me to the medical committee. Since the examination room is small and there is no physical need for extensive walking I do not need to use a wheelchair for preventing future pain. Instead I entered the room with a wheelchair as a symbolic act in order to validate the claim that I in my life am in need and utilize a wheelchair. In the committee I required my wheelchair to be present to accompany my testimony on pain and wheelchair use. I am expected to demonstrate to the doctors my everyday need and to let them experience me using the wheelchair.

The use of a wheelchair in front of the medical committee becomes demonstration of disability out of context. I directly interact with the committee for approximately the ten minutes that I meet with them for the direct examination. I know however the power of the committee and the ways in which it could profoundly influence me afterwards. Its influence – in a similar way to the medical label– crosses over the boundaries of time and space. My intentions were to make my disability transparent, to ensure that when the doctors would examine me they would see me, note my pain, and register my wheelchair as a concrete and tangible reality. It was my need that my disability of mobility would be present in the examination room for those ten minutes I was allotted that would determine my status and rights.

It is afternoon. I am in the waiting room. I am sitting in a motorized wheelchair. My mother is sitting in a chair next to me. Strangers are sitting nearby. There is not a lot of conversation. I am stressed. My mother offers me a drink. I refuse. She brings the receptionist my ID card. Approximately fifteen minutes later a familiar name is thrown into the waiting room. It is my name. “Yes!” My mother calls and signals for me to move forward. Me and my mother stand outside the door of an adjoining room. The door is opened by a man dressed in white. The two of us are allowed to enter. A small room with bare walls, a long table is in the center. Against one wall is a folded drape under which someone is expected to cover up while laying the bed.

The staff consists of four people, three men and one woman. The woman is sitting with her back to the bed and she is the one assigned to record that which takes place. The same man in white approaches me, asking didactic short questions. “Are you able to walk?” “Yes.” “So why are you using a wheelchair?” “Because I am in pain,” I reply. This is obviously not the right answer I tell myself, feeling the pressure is building in me. I am getting increasingly more distressed.

“Lie down on the bed.” I get up from my chair carefully and move slowly to the bed that is a meter away. I lie on it. “Get undressed.” My mother feels uncomfortable for me. The doctor seems to feel her discomfort and responds “we are all doctors.” I roll down my pants. He begins to push, pull, stretch, lift, bend, and swing my bare legs. He is hurting me. A sharp cry comes out of me. The woman that is sitting beside the bed turns to me quickly, terrified. I don't resist; the doctor is allowed to do to me what he wants.

I was advised by people with extensive experience in this area that in the medical committee I need to scream strong and fast, to indicate to them that it hurts, even before it actually hurts. There were times that this is what I did. But the doctors always remained impassive. Even when the screams were real and uncontrolled they remained apathetic. Maybe they are used to painful screams, perhaps they think I am lying and that they are being deceived.

This time, when his fingers enter into me pressing into my body as deeply as possible, I strengthen myself and despite the pain I hold back the cries. I breathe deeply, quickly.

The man leaves me. “Good, you can get dressed.” He goes to the woman to record his assessment and the protocol that follows. My mother helps me get dressed. Words that I am not familiar with are thrown in the air. They encode me. I am sitting on the bed, looking at them. “We finished, you can go.” I return gingerly to my wheelchair. Another man, also dressed in white, sits behind the table and looks at me with confusion. Me and my mother leave the room. I am still in pain from the doctor touch. I enter the nearby bathroom with my wheelchair; in the back of my mind through the pain even though I can physically get up, I am still anxious and hesitant to get out from my wheelchair, lest they view me as an imposter.

The small and isolated room of the medical committee can be understood as expression of the individualized medical model of disability.[xxviii] This model can be identified as majoritarian, one that presumes a supposed essential ontological entity within which disability is located – as a priori. In accordance with the medical model it is expected that it is just me, or more accurately, just my body, in the examination room. The committee relies on an isolated arena, a narrow and unnatural time and space, cut off from the examinees daily life and completely detached from the social context. As an examinee I am expected to demonstrate my disability as if it is a state of being; a concrete property of my body. My reality is cut off. I am measured by them as a body with a disability that is assumed to be a clear and fixed.

In contrast with the individualized medical model embodied by the medical committee, the critique of the committee stems from the broad field of disability studies that advocates for the social model of disability.[xxix] The social model of disability highlights the very social context which the medical committee seeks to dissociate from. Within the social model of disability, disability is re-conceptualized as socially constructed and contextual.

In the medical committee the role of healthcare professionals changes in a critical way, particularly in contrast to therapeutic situations. In the therapeutic relationship, relevant healthcare professionals are obligated and committed to provide for me, the patient, services to address my needs. Specifically the therapeutic relationship between doctor and patient is based on some form of trust.[xxx] The oath taken by the doctors is premised on the assumption that he will treat me well and that in return I can be honest with him.

In the medical committee the role and thus the dynamics and expectations change completely. The same physicians play the role of gatekeeper. In the committee, the doctor is the one who has to define and categorize, and through it determine eligibility. He is obligated to translate his findings into a formal evaluation and assessment directed not to the person who came to him in the first place, but rather to the state, to the same Insurance Institute that employs him.

The medical committee is not driven in an objective manner; there are clear interests. On one end there are doctors that are employed to be the arm of the state, to limit benefits and thus minimize financial costs to the government. On the other side there is an examinee that seeks to maximize the disability percentage assigned to him by the committee which will in turn maximize the benefits he is eligible for. This creates a space and assumption of doubt and mistrust. I know that if I do not prove my eligibility and worthiness of disability to the investigating doctors and if I do not give them the supporting evidence including the medical references and certificates of approval they will reduce my benefits.

In the tense contact between myself and the medical committee my testimony of pain as the reason of me using a wheelchair becomes irrelevant. Through the committee I had the feeling that pain was not the answer they were looking for. Minoracy knowledge, my first-person account and claim of pain had no validity in the medical committees. It could not be absorbed within professional knowledge. My words, my knowledge, my experience are silenced and nullified. The committee was in need of concrete physical evidence of my difficulties that would not be mediated or transmitted by me, the subject. The social structure of the committee made me an untrusting subject which can misleads the doctor and contaminate the examination. They are in need to attach my pure body; my physical body that the clinical gaze supposedly know how to disclose. In this space my testimony of having pain, screaming that expresses physical pain and seeing me in a wheelchair can be perceived as deceiving because I have the ability to artificially produce them. In search for the truth those elements needed to be valid by the professional knowledge and in my case by physical examination of my body practice by a trained orthopedist or even better vilified by an x-rays.

The distrust in the medical committee is bidirectional and places both the examinees and the doctors in a position of tension and vulnerability. Both sides acknowledge that what is happening in the examination room is not necessarily connected to the cultural category of truth yet both sides are attempting to grab hold of and maintain the appearance of truth. While they start their evaluations from a place of distrust I also am lacking faith in the possibility that the doctor will try to meaningfully see my reality and the difficulties I experience. I do not trust that the evaluation will result in my being eligible for all of the services I need.

And so in an exaggerated manner in front of the doctors' judgmental gaze I performed my daily experience of disability and pain. I masquerade myself and become disabled in a minoracy move. The display of me in the medical committee produce multiplicity of confusing messages about what is visible, what is essential, and what is really exist. It mixed up reality in a way that made it no longer possible to define truth and false. In the metamorphous movement there was confusion and it became very difficult to identify the truth and facts about my body and identity.

Concluding Remarks

Each of the three types of knowledge discussed above creates a different affinity with majority and minoracy. The first type of knowledge, common knowledge, sticks my body with the label that categorizes me as “little”. This act of defining in itself can be understood as majoritarian but simultaneously this type of knowledge contains within it the lines of flight to minoracy. As long as knowledge about my body is based on the question of “why”, the categorizations remain unstable, flexible, and not final. Professional knowledge is characterized much more clearly as majoritarian. Under the framework of professional knowledge, the medical establishment sets and reinforces my body under the pathological evaluations and generates around it formal knowledge which flows beyond the doctor’s office outside into different spaces. The last type of knowledge is first-personal knowledge and expresses minoracy as a changing movement that cannot be attributed to organized or fixed structures. The physical pain of my body undermines the power in the concepts of knowledge and generates a hybrid concept of minor knowledge.

The medical committee, operated by the state, requires a ruling about my body, a ruling of my body as a disabled body. The state seeks to define me and I am required to assimilate in their majoritarian order. Out of need to receive benefits, my performance in the medical committee includes an extreme and radical performance. The masquerade that I performed turned me into a minor character that was successfully able to evade the tests of truth and falsehood. As a result of this, the committee produces two parallel processes, one of them driven by major politics and the other expressing becoming-minoritarian.

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[i] Zehavi, O. (2010). Minoracy. *Mafte'akh*, pp. 38-39

[ii] See especially, Deleuze, G. & Guattari, F. (1987). *A Thousand Plateaus: Capitalism and Schizophrenia*. Brian Massumi (trans.) Minneapolis: University of Minnesota Press.

[iii] See their book title, Deleuze & Guattari, ibid

[iv] Ibid, p. 291

[v] Buzard, J. (2003). On auto-ethnographic authority. *The Yale Journal of Criticism*, 16(1), 61-91.

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[vii] Reed-Danahay, D. (1997). *Auto/Ethnography*. New York: Berg.

[viii] Ellis & Bochner, ibid

[ix] Buzard, ibid

[x] Coffey, P. (1999). *The ethnographic self*. London: Sage.

[xi] Deleuze & Guattari, ibid, p. 3

[xii] Garland-Thomson, R. (2009). *Staring: How we look*. New York: Oxford University Press.

[xiii] Fanon, F. (1967). *Black Skin, White Masks*. Charles Lam Markmann (trans.). New York: Grove Press.

[xiv] Garland Thomson, R. (2000). Staring Back: Self-Representations of Disabled Performance Artists. *American Quarterly*, 52(2), June, pp. 334-338

[xv] Deleuze & Guattari, ibid, p. 291

[xvi] Wendell, S. (1996). *The Rejected Body: Feminist Philosophical Reflections on Disability*. New York: Routledge. P. 117

[xvii] Foucault, M. (1973). *The Birth of the Clinic: An Archaeology of Medical Perception*. A. M. Sheridan (trans.). London: Routledge.

[xviii] Wendell, ibid, p. 134

[xix] Linton, S. (1998). *Claiming disability: Knowledge and identity*. New York: New York University Press.

[xx] Ibid, p. 30

[xxi] Wendell, ibid

[xxii] Scarry, E. (1987). *The Body in Pain: The Making and Unmaking of the World*. New York: Oxford University Press.

[xxiii] Deleuze & Guattari, ibid, p. 40

[xxiv] Siebers, T. (2008). *Disability Theory*. Ann Arbor: University of Michigan Press. P. 8

[xxv] Ibid, p. 10

[xxvi] Siebers, ibid, ch. 5 (pp. 96-119).

[xxvii] Ben-Moshe, L. & Powell, J. (2007). Sign of our times? Revisi(tin)g the International Symbol of Access. *Disability & Society*, 22(5), 489-506

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[xxix] Ibid

[xxx] Parsons, T. (1951). *The Social System.* New York: The Free Press.