



**UNIVERSITY OF CAPE TOWN**  
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

**This disabled body: An autoethnographic study of disability in post apartheid South Africa.**

by

Siwongiwe Mata

MTXSIW001

Minor dissertation submitted in partial fulfilment of the

Master of Arts (MA) degree in Social Anthropology

Department of Social Anthropology,

Faculty of Humanities

UNIVERSITY OF CAPE TOWN

Supervisor: Kharnita Mohamed

February 2023

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

## **Plagiarism Declaration**

I, Siwongiwe Mata, declare that, except for sources used or quoted and duly acknowledged, this dissertation is my own original work, and that it has not previously been submitted for any degree or examination at any other university.

S. Mata

## Acknowledgements

This dissertation, every word and every idea that went into it would not have at all been possible without the guidance and insight of my incredible supervisor, Kharnita Mohamed. You have become someone I consider a friend. I am immeasurably grateful to have been under your brilliant, compassionate, patient and kind wing.

To my participants, myself included, I will not name you here. Keep taking up space and disrupting the comfort of not including us. We deserve to be here.

To Mantoa, thank you for walking with me and literally supporting me every step of the way. I can't do anything without you.

To Rafiki and Rainbow, you weren't mentioned here, but the two of you made every path walkable and every journey smoother.

To my classmates-turned-friends, this master's journey was so much softer with you in it.

To Makaziwe Stofile, thank you for being with me every step of the way. Every email, every paragraph, every sentence you proof-read and every word of encouragement from you in this process is why I was able to complete this. Thank you so much.

To my friend and colleague, Tamia Botes, every single thing you did for me in this process? I have no idea how to express my gratitude, onsekind!

To Beyoncé, thank you for you and for releasing Renaissance in June and encouraging me to be my best queer self. I know you'd be proud of me!

Finally, to me, you did it!

## ABSTRACT

Disability lies at the heart of a complex framework of knowledge and identity in post-apartheid South Africa. In this autoethnographic study, personal reflections on my history as a queer, Black, physically disabled individual are retold and compared to her current personal narratives to answer questions about disability in a contemporary South African context. Comparing my current experiences to my past, the question of how stigma manifests when considering the relationship between the disabled, other disabled people and the able-bodied is explored through looking at my relationship with my assistive devices. This catapults the reader into understanding how bureaucracy emerges in disabled life, as the assistive devices can be viewed as mediators of the relationship between the disabled and the world. The question of what community means for disabled people is explored in an attempt to articulate the complexities and nuances of disabled identity. Most hegemonic disability theory often does not account for the complexities and flexibility of the everyday life of a disabled individual. Reliant on memory, this study illustrates how crucial personal and intersectional reflections are in establishing how stigma lives in the stigmatiser and the stigmatised in different contexts, shaped by time and experiences. Further, this thesis demonstrates the value of considering events across time and that ableist interactions and experiences are not static but are dynamic and are constantly reshaping social relations.

Contents

<b>Introduction .....</b>	<b>6</b>
<b>Methodology and methods .....</b>	<b>11</b>
<b>Why autoethnography .....</b>	<b>12</b>
<b>Methods.....</b>	<b>15</b>
<b>Ethical considerations .....</b>	<b>16</b>
<b>Chapter 1: Exploring internalised ableism through Arthur .....</b>	<b>18</b>
<b>Naming assistive devices .....</b>	<b>19</b>
<b>Arthur.....</b>	<b>22</b>
<b>Arthur in the present day .....</b>	<b>23</b>
<b>Stigma.....</b>	<b>24</b>
<b>Internalised stigma .....</b>	<b>25</b>
<b>Disability and childhood .....</b>	<b>26</b>
<b>Chapter 2: <i>Alls My Life I Has to Fight</i> .....</b>	<b>32</b>
<b>“Looking” disabled.....</b>	<b>36</b>
<b>My experience of intersectionality .....</b>	<b>38</b>
<b>Chapter 3: Dating and Stigma: On care and desirability while disabled .....</b>	<b>41</b>
<b>Chapter 4: Community.....</b>	<b>52</b>
<b>Community in childhood .....</b>	<b>55</b>
<b>Ubuntu.....</b>	<b>56</b>
<b>Conclusion.....</b>	<b>63</b>
<b>References .....</b>	<b>66</b>

## **Introduction**

This thesis focuses on how disability and disability theory manifests in my life as a Black, queer, disabled individual. The thesis is autoethnographic and comprised of personal reflections presented as ethnographic vignettes from my history. Additionally, more recent occurrences are compared to the past to locate the complexities and entangled truths about disability. That is, how I viewed disability as a child and then as an adult. As Reynolds Whyte & Ingstad (2007) remind us, comparison is necessary for interrogating disability. Though, they meant across cultures, it inspired me to also compare across my lifetime. The complexities of living a life where I was once able-bodied and no longer am, are manifested through my daily experiences and interactions. Although not necessarily generalisable, I however felt it important to unpack these complexities and make sense of them with the use of theory to provide answers to questions that critical disability studies can provide. Like Harriet Cooper in *Unsettling Distinctions* (2020) I am by no means attempting to provide a narrative that accounts for every person with a disability, but like Cooper (2020) it is important to tell “my story. From my perspective.”

I was born in the Eastern Cape to Xhosa parents. My mother and father separated, and my mother moved with four-year-old me and my older brother, to start a new life in the Northern Cape. The dominant languages spoken in the Northern Cape are Tswana and Afrikaans. Which meant a barrier for my mother, but as an impressionable child, I quickly learned the languages and became integrated into a predominantly Setswana-speaking community. During apartheid, the government introduced numerous legislations based on racial classification. The legislative basis for racial classification during apartheid was the Population Registration Act No. 30 of 1950. This Act divided the South African population into three main racial groups: Whites, Natives (Black Africans), Indians and Coloured people (people of mixed race) (SAHO, 2015). Race was used for political, social and economic purposes. Without re-enforcing racial categorisations brought on by apartheid, I wish to highlight that there are different ethnic groups who share values, practices and a language (SAHO, 2015) and are located in specific provinces in South Africa. What is important to mention, though, is that due to policies such as Apartheid Spatial Planning under the Group Areas Act of 1950 and phenomena such as moving to Kimberley to work on the diamond mines, for example, many people who were racialised due to apartheid classification were forced to go to places that were unfamiliar. These classifications

are dependent on contexts and the times. What often happens when you move to a province with a different ethnic group to your own (a Xhosa family from the Eastern Cape moving to a province with mostly Tswana people) is that finding people who share your ethnicity means building community with them and gravitating towards them. I would learn this every time I moved to a different community.

The community that my family and I built with another Xhosa family in the middle of a Tswana township had a father, who was a respected pastor, family man and was also an amputee, Tatomkhulu. Arthur, a mentally disabled man who also lived in that neighbourhood was feared by young children and women, as community members claimed Arthur chased young girls and harmed them. Reynolds Whyte & Ingstad's *Disability Connections* (2007) invites us to think alongside 'circumstance' and 'context' to make sense of history and the now. Reflecting on the juxtaposition of Tatomkhulu and Arthur and how they had each affected me illustrated how differences in the contexts and circumstance of different disabilities work to produce internalised narratives of disability.

I stayed with my mother in small towns called Hartswater, Postmasburg and Douglas consecutively for about four years each before settling in the neighbouring town of Kimberley where I completed the latter years of my high school career. By the end of my third year at The University of the Witwatersrand in Johannesburg in 2018, after having been to many doctors and traditional healers trying to figure out the reason for my imbalance and lack of coordination, I was diagnosed with Cerebellar Ataxia. What was offered by traditional healers were rituals to "correct" or "fix" the "problem". I first saw a General Practitioner who referred me to a Neurologist who misdiagnosed me with Multiple Sclerosis (MS). A year later I saw a specialist Neurologist who diagnosed me with Ataxia. I was then advised to seek Occupational and Physical Therapy to treat and manage it, as it is incurable. The emphasis on the idea of cure versus treatment is evident in both Western medicine and traditional healing. The medical model of disability, by extension, articulates disability as a phenomenon to be cured and treated (Marks, 1997), similar to traditional healing.

What the difference between traditional healing and Western medicinal practices illustrated were two different schools of thought, though based in different ontologies. Traditional healing practices were focused on my ancestry, bloodline and the actions of my ancestors and sought to cure my disability with slaughtering and rites. While Western medicinal practices were of the stance that there was no treatment for my condition. It was a result of a mutation in my genes that I had inherited from my paternal side. My mother and father were separated, and my father died when I was fourteen. The onus was on my mother to find the answers and healing from the traditional healing route to determine the cause and cure for my "problem". I underwent many invasive and uncomfortable rituals with the hopes that I would be able-bodied at the end of it. The same invasiveness and discomfort existed in mainstream medical examinations that I underwent.

Davis (1997) speaks about how seeing disability as a “problem” is directly linked to ideas of normalcy that exist around the disabled person. Reynolds Whyte & Ingstad’s (2007) work also illustrate that normalcy is closely tied to ideas of personhood, an accumulation of factors that members of a community have and which determine whether they consider an individual fully *human*. These ideas of personhood illustrate who we give *full personhood* to (Reynolds Whyte & Ingstad, 2007). This observation along with the mindfulness of those ideas of personhood steered the writing of the chapters as there were resonances with my own experiences. As an able-bodied person of a community where I encountered two different disabled people, whoever I gave full personhood to, depended on what I had taken from my community’s behaviour. It was instilled in me who to fear and who to respect, even without being told to do so in those exact words. From a young age I had already been socialised into the profound gendering of fear. Gendering manifested again when I went to my paternal family and during the ritual that would “fix” the “problem”, my father’s brother asked the ancestors that I would be healed so that I could be a good mother and wife one day. My mobility was linked to my predicted capacity to be domesticated and perform the duties that were connected to my womanhood. The fear for Arthur and respect for Tatomkhulu, my friend’s father, illustrates who was given personhood and to what extent. I carried Arthur the man into my own personal relationship with disability and he would materialise into my relationship with my wheelchair, and show me how ableism became internalised and how my ideas of personhood moved.

After being diagnosed with Cerebellar Ataxia, I was advised to use a crutch/walking stick to help me walk and balance, I eventually began using a crutch/walking stick every day. Because of the permanence of the crutch/walking stick, I began to consider the crutch/walking stick as an extension of me. I gave it a name. Naming my crutch/assistive devices brought up questions around the relationship between the physically disabled person and their assistive device. But also, the fact that there are ways that I am perceived with and without the walking stick/crutch. I began to think of the performance of disability. Located in these questions was the idea that, in public, I had to pick an identity and stick to it. That is, there are places and instances where if I was seen using a walking stick/crutch once I would have to always be using it. In addition to the hardships of navigating the physical world that are faced by disabled people, having to add explanations about it and more for the people watching would simply mean more hardships. What has been a constant throughout this dissertation has been dissecting and questioning my experiences in relation to existing theory to answer critical questions like these about disability.

After obtaining an Honours degree at The University of the Witwatersrand in Johannesburg, I enrolled for a master's degree at The University of Cape Town (UCT) in the following year (2020). I was living in a new city and was hopeful about being in a new space where no one knew me, my history or that I was not visibly disabled until two years ago. This became a point of interest to me, as well as evoked emotions such as disappointment and shame. I had to unpack the disappointment and shame which led me to understanding the system of stigma (Goffman, 1963). Goffman's (1963, 3) early formulations of stigma as "an attribute that is deeply discrediting" illustrates the idea that having the marker of disability as an identity, results in the disabled person (the stigmatised) being isolated under just that one identity. Goffman (1963) illustrates this by saying that the stigmatised person is reduced from "a whole and usual person" to a "tainted, discounted one". Although Goffman wrote this nearly 60 years ago and, in another context, it resonates with me as a Black queer woman.

Moving around different settings in public spaces with an assistive device, the assistive device becomes a marker of my disability and introduces me to the world before I even open my mouth (Davis, 1997). Other markers of identity, such as gender, race and perhaps class come

secondary to the visible disability. It is not necessarily always the case, however, as disability can be made visible by merely the way that one moves. I noticed this much more when moving at restaurants and my residence. Primarily, in my interactions with a Xhosa security guard at my UCT residence led me to think of the stigmatiser and stigmatised relationship. My expectation was that our shared Xhosa identity would humanise me to him and prompt him to be more pleasant towards me, however as you will read about in the chapters of this dissertation, that was not the case.

Ableism, a set of beliefs that view disability as a counter-image to able-bodiedness and, hence, as deviance or unwanted difference (Campbell, 2009), is the overarching theme of this dissertation, as it can be located in every experience that I unpack. Ableism can thus be viewed as the system from which other systems that it critiques emerge. Ableism can further be internalised (Campbell, 2009), in the way that even I have, and live inside the disabled person. It can also be perpetrated, when internalised, by the disabled person towards other disabled people. It is, among many other systems that emerge from it, why there are assistive devices that disabled people do not want to be seen with, for example. And the reason behind me thinking of Arthur from my childhood when I received an assistive device that I did not like the look of. This is a phenomenon I dissect in the forthcoming chapters which I below.

In the first chapter of the thesis, I discuss my methodology, the rationale for autoethnography and why centring my own narrative was a viable method. The chapter thereafter delves into assistive devices and the meanings behind naming them. The naming of my own assistive devices which brought questions of internalised ableism to the fore, is interrogated. The second chapter discusses bureaucracy and how it functions in different contexts which are shaped by age, gender, class and ability as my encounters with security guards and other disabled people show me. Thereafter, the third chapter discusses ideas of desirability in conversation with stigma, illustrating that desirability is profoundly shaped by able-bodied people's view of disability where even the care afforded to a disabled person can be shaped by the stigma and ableism attached to that desirability. The last chapter focuses on community, ideas of respectability and *ubuntu* told through the story of Tatomkhulu, a respected member of the

community I grew up in juxtaposed against Arthur from the same community and how I related to him.

### **Methodology and methods**

On the 15<sup>th</sup> of March 2020, following the emergence of COVID-19, the President of South Africa announced a nationwide lockdown of 21 days in which everyone was ordered to stay at home. People were given a 72-hour grace period to travel to the respective provinces and towns where they wanted to spend the duration of the lockdown. Some of the regulations that were put in place was to adopt social distancing as a general practice and to wear a mask when interacting with another person or people. During that 72-hour period, I, too travelled from the Western Cape to my home province of the Northern Cape. To assist me in moving around in public, I rely on objects to lean on, such as railings, walls, pillars and sometimes people. During my travels, in this period, it became scarier, as there was a higher possibility that I could contract COVID-19 from touching public, unsanitised objects. During my stay at home that kept getting extended due to the constant rising of COVID-19 cases, I thought about how the presence of COVID-19 further alters how I move about in public and questioned whether the same was true for other disabled people. While I was confined to my home and only went outside after a month, I thought about the private versus the public life of disabled people, and what it means to not have to be seen and how past experiences inform present ones. I moved back to Cape Town in July of 2020 after being invited back to residence to continue my studies.

Another crisis emerged when a fire started on the 18<sup>th</sup> of April 2021 on the slopes of Table Mountain and destroyed some of the buildings on the campus of the University of Cape Town. Students from several UCT residences - one of which I resided in – were sent to hotels in the city for a few nights to get away from the area of the fire and the smoke that could be hazardous.

As a disabled student registered with UCT's Disability Service, along with six other disabled students, I was taken to a hotel in the city. It was there where I met, interacted with, and developed an "us" with other disabled people for the first time. Getting to know disabled people was very different across my life and meeting these friends in 2020 differs distinctly from my first or formative encounters with disability.

During my childhood, the first disabled people that I encountered were Arthur and Tatomkhulu, whom I speak about extensively in the following chapter. However, I was not disabled in those years and did not identify with other disabled people. Nor did I have disabled friends or notice disability until I became disabled. I quickly formed friendships with the other students from the Disability Services where we shared meals, fears and concerns, critiques of the situation and laughter. Although this thesis is dominated by autoethnography, the fire allowed me to experience the crisis through other disabled people. Being around other disabled people for the first time brought about comfort during a time of crisis. I delve into that as one of the themes that emerge from the coming autoethnographic reflection.

### **Why autoethnography**

In documenting the lives of disabled people, reflexivity has been central to the exploration of what it means to do fieldwork that incorporates autoethnography from the vantage point of a researcher with a disability, whatever the focus of their research (Ginsburg & Rapp, 2013). The idea that disability is a valuable and necessary critique of the functioning of society is substantiated by Colligan (1994 in Ginsburg & Rapp, 2013, 57). Given her occasional physical dependence on community members for help, her disability was not a form of “privileged access”, but rather how our “own bodies potentially enrich anthropological insight and experience” (Colligan, 1994, 9). Ginsburg & Rapp (2013) further validate the use of a reflexive perspective by stating that a reflexive perspective deepens the insights that anthropologists bring to their fieldwork and analysis. In Couser’s (2015) *Disability and (Auto)Ethnography* he states that there are ways in which tools for inclusion for people with disabilities can stand as reflections of a community’s treatment of disability.

Disabled people are not a homogenous group and do not share a single condition. Disabled people cannot be — nor should they be — represented as a monolithic community. The language used to speak about disability is unpacked by scholars like Erevelles (2011) and Mohamed and Shefer (2015) to substantiate their reflecting on intersectional ways of engaging disability and gender. These critical theorisations allow for the emergence of definitions, language and identities that do not reproduce power dynamics (Erevelles, 2000, 26). For example, Couser (2015, 123) shows and describes the ways in which the physically impaired have tended to look down on the mentally impaired. Life-writing has important tools for

unpacking disability (Couser, 2015). As a Black South African queer woman who is also disabled, my identities intersect in ways that catapult one into thinking critically about the world. This thesis illustrates the value of life-writing to disability autoethnography have much to offer each other. Additionally, there is a shortage of humanising representations of me in academia and literature. That kind of representation requires a consciousness and mindfulness of the internal politics of a community divided, in many ways, by social categorisations such as race, class, gender, ethnicity and sexuality. These social categorisations that make up an individual overlap and form unique identities and experiences, as Crenshaw's (1989) teachings on intersectionality offer. Crenshaw's (1989) formulation, however, was not about uniqueness, that is, disability or identity as diversity. Rather, it was about systems of oppression that interacted to produce experiences of oppression. Thus, Black women who are able-bodied and Black disabled queer people have experiences that are different from each other but connected by their relationship to oppressive systems.

The idea of conducting research on a group of people that share similarity and experiences with you is open to much critique, as this occurrence often runs the risk of causing the researcher to overlook objectivity. What this means is that the researcher, as someone who shares similarities and experiences with the group of people that they are conducting research on, is at risk of imposing their own beliefs, opinions and ideas onto the group. This could result in the researcher inadvertently shaping the narrative. Feminist theory, however, vouches for the idea of a "strong objectivity" saying that objectivity is not only desirable but also possible (Harding, 1992). As echoed in the works of Colligan (2001), sharing similarity with the participants is an extension of familiarity and community in a way that allows the researcher to gain valuable insights through shared experience.

Evidently, the abovementioned points to age-old debates in anthropology on doing research at home and connected to the idea of making the strange familiar and the familiar strange. In newer works such as that of Carolyn Ellis' (2013) chapter in the *Handbook of Autoethnography*, she relates that her spelling of the word 'autoethnography' without a hyphen is indicative of her view of it as a concept on its own, that can stand alone. In her essay, '*How Native is a Native Anthropologist?*' Narayan (1993) argues against the rigidity of a distinction

between "native" and "non-native" anthropologists. Instead of the paradigm stating a distinction between outsider/insider or observer/observed, Narayan (1993) proposes that we view each anthropologist in a different way. Narayan (1993) suggests that we view each anthropologist in terms of shifting identifications in a field of observing and unpacking communities and the power relations within. In this way life-writing or, if you like, self-documentation is a viable research method that goes hand in hand with autoethnography. Robert Murphy's (1987) autoethnographic work, *The Body Silent*, uses the concept of liminality to describe the subtle nuances of disability. Murphy's (1987) autoethnography illustrates the immeasurable value of life-writing in under-documented life conditions. Seeing that being a disabled person is a marginalised and under-represented category in society and literature alike, it is necessary to have the lives of disabled people documented as they exist within a white supremacist, patriarchal, capitalist, heteronormative and ableist society such as South Africa. It is particularly important to document the self and narrate one's own narrative, which further emphasises the importance of autoethnography. Rose Richards (2008) problematises how writing on disability is often from the perspective of an outsider, thus advancing autoethnography. Given the context of COVID-19 and prioritising online research where minimal physical/personal contact is required, I decided that the best way to conduct my research was through using autoethnography.

This dissertation relies heavily on emotions, reflexivity and memory work. Goodley, Bates & Runswick-Cole (2017) frame affect in the context of critical disability studies is the idea of "feeling disability". It encompasses, as Goodley *et al.* (2017) continue, the illumination of the lives, hopes and desires of young people with - what they refer to as - 'life-limiting' or 'life-threatening' impairments. Critical studies of disability, which allow for the unpacking of robust and dense theory attempt to bring forward that feelings and affect, by extension, become what is located in the social interactions of disabled people and shapes the stories and narratives that shape disability and its meanings.

The emotional aspect relies, on vulnerability and I express that vulnerability throughout this dissertation to (re)imagine, as Boon (2013) states, the relationship between the Self and the experiences that leave feelings of vulnerability and stigma. The emotions that live inside me

(the Self) and for locating and unpacking stigma. They also function as antennas for understanding the ways in which stigma lives in the Self and, in turn, how I recognise it in my experiences and that of the people that I interact with.

When it comes to the Self and the antennas that make up the Self, one can deduce that this is an emphasis on looking inward. When one is looking inward towards one's psyche, one's history, emotions and vulnerability, it is a good starting point to understanding the ways in which those inward vulnerabilities and emotions can, in turn, be turned outward. The act of being turned outward means that one is able to use what comes from inside, that is, vulnerabilities and emotions to navigate and feel, if you like, external factors such as stigma and ableism and the ways in which one experiences those. Furthermore, those antennas allow one to unpack the meanings located where what is inward meets the outside and what the meanings are behind those complex interactions.

It is through the value of hindsight and reflexivity that one takes a different look at one's lived experience. These lived experiences present multiple intersections through individual and collective narratives together with continuously acknowledging your own positionalities, experiences, roles, and political and theoretical frameworks as a researcher. Goethal *et al.* (2015, 82) articulate this point of view, stories of lived experience as important to both the subject and the researcher, as they are co-constructed and negotiated between the people involved as a means of capturing the complex, multi-layered and nuanced understandings.

## **Methods**

As my autoethnographic method, I journaled and relied on memory of past experiences. I planned to conduct semi-structured interviews with my participants using my experiences as a guide. I also focused on my experience of two disabled men from my childhood and juxtaposed them to compare, contrast and conceptualise new ideas. The journaling and, by extension, questions to my participants that emerged however, were centred on forming community against the backdrop of the pandemic. What the overarching autoethnographic component allowed me to do was gain comparative insight between my past and my present. The friends made during the fire, live in my university residence and we often visit each other's rooms.

One participant and I, without planning, were often in the same space, and it was unplanned. I found value in the natural flow of conversation and rapport between us.

A participant in my residence did not have a disability that caused them to be immobile, however they used a hearing aid. It was important to include a variety of experiences of disability that spoke to varying class, gender and race positions, thus an unstructured interview we had brought out themes of desirability, dating and stigma, which I elaborate on in one of the chapters of this thesis.

### **Ethical considerations**

Even though this is an autoethnographic thesis is comprised of my experiences, there are scenes that include other people, that is, my participants and people who I lived in residence with. I used pseudonyms in ethnographic vignettes and excerpts from scenes that included my participants. In addition to that, since disabled people often have very distinct markers of their disability – such as a distinguished assistive device – which would compromise their anonymity, I did not highlight those to avoid revealing their identity.

The ethics of the Self and the future Self come into question. When researching about the Self in this way, most of the work relies on vulnerability and memory work. Considering past memories and encounters that have shaped my life in profound ways and linking those to existing disability theory and conceptualisations, required a lot of vulnerability. Some memories carried shame and triggers thus, it was necessary to consider what those effects would be on my Future Self. I was seeing a therapist and talking to people that I know. The question of vulnerability and my Future Self had an even stronger pulse when I shared information about my personal dating life in Chapter 3, as what I shared made me question whether my truths would be received with empathy and safety by the reader.

The disabled people from my childhood, Arthur and Tatomkhulu, their stories and history were based on places that I occupied with them when I was a child. Arthur's real name is not used, even though it is not a unique enough name to be able to identify a single person from nearly

two decades ago, it was still necessary to conceal his identity and use a pseudonym. Tatomkhulu, on the other hand, is the IsiXhosa word for ‘grandfather’. Thus, their anonymity is protected. Nomuzi, Zikhona and Melikhaya are also pseudonyms. Disabled people often have unique assistive devices and features as markers of their disabilities, thus I attempted to not highlight those, as there are only a few mentioned. Some of the interactions were impromptu and I got informed consent to use those.

While mourning the absence of face-to-face interactions during the research process, which would have allowed me to see body language and natural movements, because of COVID-19 face-to-face interactions happened only by chance amongst people I was already in residence with. That limitation produced intensive reflection and allowed me the opportunity to learn how ableism lives within you and become alert to how you navigate the pervasive disability discourse. The following chapter unpacks my relationship with assistive devices, the act of naming them, and how it links to internalised ableism and stigma in intricate ways.

## **Chapter 1: Exploring internalised ableism through Arthur**

Living in a disabled body and reflecting on those experiences in an autoethnography, lead to questioning the many personal and intimate truths inside of me. The type of questioning unexpectedly, although inevitably, forced me into realisations about how the ableism that I recognise in my daily experiences is very much internalised, as well. A hindrance to accessibility is one of the ways that ableism manifests and can result in negative feelings. A sign of the extent to which I had internalised ableism is in the way I name my assistive devices which reflects the state of my psyche, and what is important to me.

I name my assistive devices because I consider them to be an extension of my body, as their use is life-long. Constantly referring to it as “it” felt uncomfortable, as there is a lingering afterthought that stays with me after whoever I talk to about my assistive device has left. “Did they leave that conversation knowing how important Mantoa is to me?” By asking that question, I was able to interrogate the motivations behind naming and the names I chose to give my assistive devices. Saying, “This is Mantoa” and that my walking stick is named after a human being was a way to say that in addition to being physically disabled, I probably also have a kinship with a human named Mantoa, which humanises me. This process of naming my devices brought me to naming a wheelchair after a mentally disabled man from my childhood named Arthur. Arthur is the personification of my internalised ableism, and this chapter interrogates that phenomenon. It is very much about the materiality of things in my world where my assistive device has a name, life story and personality. Watermeyer’s (2006) focus on the psychoanalytical nudges us into not overlooking the intimate and personal, mental and emotional implications and occurrences that experiencing disability brings forth. By this token, this chapter will include how certain beliefs and narratives reinforce the stigma that engulfs people with mental disabilities.

Having Cerebellar Ataxia causes deteriorating mobility, which I have experienced, as well as daily changes like needing a wheelchair for longer on some days and sometimes not, means that the world is different depending on the assistive device that I use. In addition to not being born disabled I used to use just a walking stick to get around, but now use a wheelchair, too. Having experienced the world as able-bodied, disabled while standing, and disabled while

sitting down has shaped how I experience and view the world, as stigma, vulnerability and naming are profoundly linked to these different modes of being and becoming.

Additionally, I have Macular Degeneration, which causes visual impairment. My Macular Degeneration is secondary to my Ataxia, as there is no assistive device except for occasionally wearing spectacles. Without spectacles there is nothing that announces that my eyes need assistance in the ways that a crutch or wheelchair does. Visual assistive aids, like spectacles are prevalent and normalised. The stigmatisation attached to them are of classist overtones. The more expensive and aesthetically pleasing they are, the more palatable they are. Spectacles do not assist Macular Degeneration in any way and me saying “I don’t see well” leads to unsolicited advice about affordable spectacles.

Being mildly visually impaired is one of the more common disabilities with access to a variety of prescription spectacles, that is, assistive devices. Thus, there is no indication that I have a visual impairment and have no marker of disability in the same way that a wheelchair or a crutch marks you as disabled. I do not think about my visual impairment until faced with a limitation, which implies normative vision.

### **Naming assistive devices**

*On one occasion at a Cape Town restaurant that I frequent, I was accompanied by my partner. It was a sunny day, and the sky was clear enough for us to wear short sleeves. The pavement felt like a mix between gravel and tar, which reassured me that the grip of the soles of my shoes would be tight. My passing thought of how narrow the pavement was, was interrupted by my partner’s “You okay?” while reaching for my hand. We made our way up the steep and chunky steps. Them first, and me holding on to them for support. I muttered “These were definitely not made with me in mind” after climbing up. The physical toll it took on me to enter the place was a small price to pay for the affordable drinks and delicious pizza they served. As we made our way through the sandy floor that had bright-coloured wooden bench-tables scattered all over it, we found an empty bench-table which placed us right under the sun’s warm gaze and waited for a waiter.*

*“Haibo, when is your leg going to heal? You are lucky you only use one crutch. I know someone who needs to use two”, said the new waiter whom I didn’t recognise as he brought two menus.*

*“Oh, I actually don’t have toes”, I lied, feeling the pangs of disrespect. “Not even a ‘hello’?”, I thought. “So, Mantoa helps me balance”, I said knowing not to be openly belligerent to someone who is handling my food. But I had to give him something in return of the invasion: confusion.*

*“Who’s that, your friend?”*

*” No, my stick. She doesn’t like being called a ‘crutch’. She prefers ‘stick’ or that you just call her by her name.”*

I have been using a walking stick/crutch to assist me in walking, remaining steady and keeping my balance since the age of 22. The crutch, or stick, rather is always on my right hand and functions as a third leg. My free hand is for balancing. When I first got Mantoa I did not want anything to do with her, because of how I looked and felt with her. When I began to use her, referring to her as “it”, the disconnection I felt with my permanent assistive device was amplified. Jacobson (2017) describes this eloquently by stating that even though assistive devices may be functional, they often become abandoned for reasons such as not being aesthetically pleasing. Suffice to say that if I had not named Mantoa, I would have abandoned her as well. Hocking (in Jacobson 2017) claims that abandonment relates to users’ perception of themselves as disabled and to broader issues of identity in relation to other people and to assistive devices. I gave Mantoa a name meaning “warrior woman” in Sesotho, as I find her aesthetically pleasing enough to be seen with in public and give a name with positive and empowering connotations. Jacobson (2017, 2) mentions the design of assistive devices being mainly for functionality and usability. The aesthetic qualities, for instance, appear to be a matter of lesser importance. In this way, assistive devices become stigmatising, which affects their users’ assimilation into their environment. It is not unusual, then, to find that physically disabled people rely on other body parts to perform tasks, rather than a stigmatising assistive device. My recognising that, for instance, the pavement near the restaurant makes the soles of my shoes have a tight grip is me recognising and acknowledging that I do not need Arthur, the wheelchair here. That is a product of the stigma associated with assistive devices in public. But at face value it is about the design element for the built environment more than the stigma. The

built environment in that particular area is not disability friendly or accessible. Disabled people have to find ways to be able to use the space with or without assistive devices that is unique to them. I convinced myself that I did not need Arthur the wheelchair here, because I did not like the look of it. This is how stigmatisation of assistive devices, and the built environment are in conversation with one another.

As you gathered from my interaction with the waiter, I do not like the word “crutch”, as it is used as an excuse. It reminds me of when people use expressions like, “Stop using apartheid as a crutch”. An excuse is negative and it being synonymous with an assistive device that equalled independence for me simply did not sit well with me. The name Mantoa has an audacious feel. The Mantoas that I have encountered are loud, audacious women who are heard and seen wherever they go. It also stands as a reminder that Mantoa is seen, takes up space and is visible. As such, it resonates even more, because I consider the outside/public as an obstacle course. A warzone. And walking around in public feels like going to war. In a way, having my warrior woman with me makes me feel armed.

Sigrid King’s (1990) analysis of Zora Neale Hurston’s 1937 novel *Their Eyes Were Watching God* dissects the concept of naming as power in the lives of the Black American enslaved people that she was writing about. King (1990) posits that naming is tied to a racial and individual identity. Stating that to have a name is to have a means of locating, extending, and preserving oneself in the human community, to be able to answer the question 'who?' in relation to others. Furthermore, King (1990) continues, William Halsey in his essay "*SignifI(cant) Correspondences*" further emphasises the importance of naming for Afro-Americans, saying that names and naming are "a heavily ritualised rite passage and theme prevalent in African culture" (Halsey, 259 in King, 1990, 683). This is evident in the relationship that I have with naming, because the ritualised process of coming to my identities as a Xhosa person in Africa: my surname, my clan names, my ancestry and so forth have a ritualised component to arriving at them. Having a name identifies you and affords you a sense of belonging. Hence, I name assistive devices because a part of me humanises them in a way that I am also humanised enough to have my names.

In an attempt to lessen the stigma and internalised ableism that ought to have governed my view of assistive devices and disability at large, the act of naming is a deliberate act of defiance. Making this known to the strangers that I encounter is an extension of the defiance and reclamation of power that is often needed when one is visibly disabled. When you have an assistive device as a marker of your disability you encounter strangers who use that as an icebreaker, so to speak. I become subjected to the invasive questioning of “what happened to your leg?” This replaces the “hello, how are you?” that ordinarily is the go-to conversation starter between strangers. The act of naming assistive devices and its value to me catapulted me into unpacking not only the meanings behind naming things, but also my relationship to the names I chose and my history with disability. What follows is a retelling of events that led up to naming an assistive device and the stigma, vulnerabilities and (internalised) ableism surrounding that moment that this particular act of naming forced me to interrogate.

#### Arthur

*The year is 2004 and I am performing a mundane task with my 7-year-old hands on the laminate patterned flooring of our four-room Reconstruction and Development Programme (RDP) home kitchen, when my friend emerges in the door frame. The streets were dusty and little children walked or ran around barefoot and bare-legged. The dustier the feet, the closer it was to the time the streetlights were going to be on, because they had played enough for that day. The dust on my friend's feet illustrated this very thing. After greeting my mother who was packing away the groceries she said:*

*“Let's walk to the shop together, I'm scared of walking past Arthur's house alone. What if he comes out?”*

*After emphasising that we had better return by the time the streetlights came on, as Arthur had become a metaphor for the dangers of being in the streets at night, my mother gave a permitting nod and off we went. My friend and I walked to the shop together to lessen the fear and anxiety that was associated with being young girls in the area. When we approached Arthur's house – an overweight elderly man with a grey beard and full head of grey hair who was always seen covered in a grey blanket, wandering about in the area and following people around – we quickly strategised on how we would make it past the house of the threat. We did not want to run into Arthur and be chased by him.*

This anecdote from my childhood is of an experience of Arthur that shaped my adult relationship to disability. I often heard Arthur being referred to as “*lehlanya*”, “*setseno*” or, in my mother tongue Xhosa, “*igeza*” which loosely translates to a mad person who wanders the streets. Almost every town that I have visited or lived in had its *setseno* or *igeza*. Apartheid spatial policies ensured that Black people were relocated by the apartheid government to townships after areas were declared “whites only” by apartheid government authorities. Such townships became extremely overcrowded and were distinctly cut off from infrastructure, urban utilities and services such as water, electricity and adequate housing, leaving people to fend for themselves (Abel, 2015). People like Arthur, who required the assistance of professional mental health professionals, in a time when there was little to no education about mental health were left for communities to project their fears onto.

To further elaborate on stigma and its internalisation, below I reflect on a wheelchair I received from the University’s Disability Service (DS). My responses to the wheelchair and how I perceived the DS’s regard (or lack thereof) for me, show that there are complex psychoaffective responses that live inside of us and require careful thinking to unpack. Arthur, the person was the image of my association with mental disability as something fearful and to stay far away from. Whilst, on the other hand, Arthur, the wheelchair became a consequence of that association and socialisation. Even though it was years later, and my context had changed.

### **Arthur in the present day**

*I was not disabled for the first two decades of my life. I have a hereditary form of Cerebellar Ataxia, which causes loss of mobility and coordination and manifests through an inability to make voluntary movements like walking, keeping my balance and hand-eye coordination. When I enrolled in the University in 2020, I looked for a disability support service that supports students with disabilities in the University and found it in the DS. I registered with the DS and was told how they provide support and what to do.*

*In 2021, I contacted the DS to let them know that I was experiencing a further deterioration in my disability. I had gotten to the point where it had become so difficult and tiring to get around that I needed to have someone there with me to perform tasks outside my residence. The DS offered to lend me a used wheelchair for the time being to assist me in doing*

*tasks that require a lot of movement and independence. I accepted the offer and the used wheelchair was brought to me a few days later.*

*After the person who delivered it left, I got visibly sad and collapsed into my feelings of being disregarded, as I looked at the old, big, grey, dirty wheelchair that left a small layer of dust on my hands. Living with a Macular Degeneration means that I cannot perceive sharp detail and have blind spots that are embedded in my vision. So, it was only upon taking a closer look that I noticed stains on the wheelchair, which propelled me into further disempowerment. “There is no way I am going to be seen outside with Arthur”, I said.*

Here I was - seventeen years after my childhood encounter with Arthur - a physically disabled adult and named an assistive device for the physically disabled after a stigmatised mentally impaired stranger from my childhood. The naming of assistive devices, as well as the phenomenology of having existed as able-bodied and disabled are points which will be discussed further in this chapter. The juxtaposition of the traumatic, fear-inducing and stigmatised figure from my childhood, Arthur, jumping into my mind involuntarily and without deep pondering becoming a name that I used to refer to an assistive device of my disability made me question whether I was unconsciously perpetuating the stigma that was synonymous with mental disability? And was that stigma in turn seeping into the existing stigma surrounding assistive devices for physically disabled people?

## **Stigma**

Goffman (1963, 3) defined stigma as “an attribute that is deeply discrediting” and proposes that the stigmatised person is reduced from “a whole and usual person” to a “tainted, discounted one”. Goffman (1963) viewed stigma as a discrepancy between “virtual social identity” (how a person is characterised by society) and “actual social identity” (the actual attributes that are possessed by a person) and argued for the centrality of face-to-face interactions. Mismatches between self and others' perceptions hold the potential to discredit individuals (Pescosolido, 2013). This interpretation by Pescosolido (2013) suggests that stigma and its discrediting of individuals relies on the absence of face-to-face interaction between the stigmatised and the stigmatiser to keep the virtual and actual social identity separate and active. On the other hand, this is contrary to how stigma manifests in intimate interactions. My naming of a wheelchair

that I would sit on and rely on for easier access to the world by the name of a stigmatised Arthur is a manifestation of how stigma can exist and manifest in intimate interactions as well.

### **Internalised stigma**

Internalised ableism and internalised stigma are a cause and consequence of how support services do not make space for the fact that disability is not a stagnant state of being. It can change, evolve and look different through time. I say this because when I had to get Arthur the wheelchair it was because of my disability not staying the same. And, the wheelchair being this dirty thing made me feel as though I was not thought of as a person whose disability could require more or a different kind of support than before. Although, it is important to acknowledge that the DS did indeed provide the best resource that they could. Thus, being given this wheelchair made me feel disrespected and ashamed instead. The wheelchair, that immediately reminded me of Arthur from my childhood was certainly not something that I would want to be seen in public with. For a disability support service to not be mindful that assistive devices ought to be aesthetically pleasing, well-kept and well-presented put shame inside my body. In other words, it felt like they were saying, “just be grateful to even have a wheelchair” and requiring it to at least be cleaned was somehow pushing it. This also speaks to the fact that disabled people who receive aid are expected to be grateful for it no matter what (Jacobson, 2010). This illustrates that disability can be a social experience and can stand as a way to critique and interrogate my internalisation of many emotions which manifest through my carrying of Arthur.

The idea that Arthur is not to be interacted with in any meaningful way or afforded any compassion by equating him with danger is so deeply embedded in my psyche – and society as a whole - that I named a wheelchair after him. This moment led me to a question and a realisation. The question of why I, a disabled person, without giving it a second thought, would name a piece of equipment that makes the world more accessible to me, after a fear-inducing mentally ill person from my childhood. The realisation that living in a poverty-stricken township led to the lives of Black people living in those townships to be products of underresourced townships engineered by apartheid (WHO, 1976). In this way, there is a lack of mental healthcare facilities, state negligence of communities needing mental healthcare and ultimately systemic and systematic ableism and social exclusion (WHO, 1976). The

aforementioned illustrates that the individualistic view of Arthur in the community completely disregards the ramifications of the system of apartheid. I will now discuss narratives of disability and the impressionability of childhood, its relation to ableism and fear, and the ways in which vulnerability of other dangers such as gender-based violence becomes entangled with stigmatisation of disabled people.

### **Disability and childhood**

I do not remember any personal interaction with Arthur that was close enough for me to get rid of the stigma that coloured my view of him. My role in the community was that of a child, a person at the bottom of the hierarchy of age and knowledge who could only rely on the teachings and shared knowledge from above. In *Critical Disability Studies and the Disabled Child: Unsettling Distinctions*, Harriet Cooper (2020) dissects disability and childhood as disability studies' explorations of power and the body. Thinking alongside the themes of power and the body allows us to make sense of the nuanced and ever-evolving manner in which disability exists in the mind of a child and how it follows them through adulthood. This meant that my perceptions and opinions were a reflection of what I was being told and taught by the adults that I came into contact with.

The ways that children navigate the social meanings and predicaments of illness, as posited by Clark (2012), is a subject not fully researched in anthropology. In Clark's (2012) analysis of representations of illness in the media, she states that the ways that children appropriate and interpret media portrayals of illness are relevant to identity and status. It is important to emphasise that disability and illness are not synonymous. However, illness as a concept stands as a similarity to disability and disability studies when it comes to analysing society, as both are about identity and status (Clark, 2012). The identity and status of a person is, at the point of childhood, largely a mirror of the teachings of the community that the child belongs to.

The perception of disabled people by able-bodied people, suggest Mitchell and Snyder (2014, 222), forms the basis of them becoming a primary object of representation in literature. The same symbolic references can emerge from the hearsay and beliefs of the community at large and also be appropriated in the same way. Mitchell and Snyder (2014, 223) continue by stating

that disability in children's stories like *The Steadfast Tin Soldier* becomes a metaphor for social and individual collapse and children absorb that representation. The consequences of being outside of the "us" that is suggested by an "us versus them" narrative synonymous with stigma and held amongst members of a community is enough discomfort to guarantee that children do not perpetuate any difference of opinion or belief about someone like Arthur.

Internalised ableism, framed as a "tyranny within" by Fiona Kumari Campbell (2009), is a ramification of the systemic exclusion manifested socially, economically, culturally, linguistically, medically and even legally that disabled people are subjected to. Internalised ableism, then, is a consequence of the systemic exclusion that disabled people are subjected to. As stated by Marks, "internalised oppression is not the cause of our mistreatment; it is the result of our mistreatment" (in Campbell, 2009: 16). Marks (in Campbell, 2009) further states that once the external oppressions that make up ableism, that is, the social, economic, cultural and other such factors become internalised, very little force is needed externally for the disabled individual to perpetuate the oppressive system of ableism or, at the very least, be submissive to it. "We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives" (Marks, 1999 in Campbell, 2009, pp 16). Campbell's chapter in Nicole Brown and Jennifer Leigh's *Ableism in Academia* (2020) emphasises that a definition of ableism that contains the simplistic "exclusion and discrimination" that we often see is missing any nuances about the processes of such systems. Those nuances and complexities that shape the lives of disabled people, how they respond to systemic exclusions and how much of it they internalise get embedded in one's psyche, as validated by Marks' (in Campbell, 2009) we hold inside ourselves the pain and the memories, the fears.... That last bit is lingering and open-ended, because fear is, in my view, a deeply personal component of being that differs from person to person. This can be applied to how my visual impairment often comes secondary to my physical disability. The aesthetics of visual impairments are more "fashionable" and, thus, palatable due to the increased commercialisation of spectacles, whilst assistive devices for physical disabilities are stigmatised.

Additionally, I suggest that ableism in all of its manifestations and personal attacks on the psyche of the disabled person, creates fear. This fear also governs the perception of disabled people towards other disabled people, irrespective of the nature of their disability – physical or mental. To emphasise, the issue is ableism – internalised ableism is a consequence of that.

Domestic violence and sexual harassment in previous decades are used as a case study by Jordan Fairbairn (2015) to make the argument that larger social issues can inform the experience of the individuals. The notion that online abuse is an unfortunate, but inevitable feature of girls' and women's online presence is being rejected by advocates and activists (Fairbairn, 2015). Rather, it is being replaced by an increasing understanding that online abuse and harassment are a consequence of broader social ills such as misogyny, racism, and homophobia, to name a few, and should be treated with seriousness (Fairbairn, 2015). Thus, ableism is not simply an unfortunate and inevitable feature of disabled people's lives, but a manifestation of systemic exclusion and discrimination. Consequently, Arthur as an antagonist from my childhood was only positioned in this way due to the ableism that shaped perceptions of mentally disabled people in communities where other members of the community are not visibly disabled or impaired. The visibly impaired member of the community, Arthur becomes a placeholder for scary consequences and is used to instil fear. The fear, which can be thought of as a synonym for ableism in this case. The fear for Arthur that I inherited followed me and was perpetuated by me without much – if any – contribution from external forces.

The fact that stigma succeeds at being internalised by barely relying on the external is one of the points that Campbell (2009) attempted to drive home. In the same breath, it is important to highlight that in addition to the component of memory and ableism being a large part of this story, it is also a story of charity and care, as well as care akin to ableism. Sonja Boon's (2013) critique of Helene Cixous' three-legged dog, a recurring symbolism in her book *The Day I Wasn't There*, which stands as an analysis of Cixous' philosophy to the articulation of a politics of vulnerability. Vulnerability, according to Boon (2013: 85), serves as a conceptual starting point for (re)imagining the relationship between Self and Other. Boon's (2013, 85) questioning of the relationship between vulnerability, longing, and stigma provides a delicate and appropriate formula for answering the questions that arise from this moment. Boon (2013, 85)

uses the English Dictionary's association of vulnerability with that which is susceptible to wounding and further to penetrability, permeability and even porosity. That which is vulnerable can be attacked, its strength undermined, as it is wide open to the world's responses, views and critiques. Thus, continuing with Boon's (2013: 86) utterances, even as vulnerability may be an opening, a wound, or a stigma, Cixous is more interested in our reaction to it: do we enclose it to avoid any possibility of contagion? Or do we permit the wound to heal, opening ourselves up to new experiences and possibilities, whether they are joyful or painful?

In this manner, Cixous assumes that vulnerability—as porosity—must be regarded as both a source of despair and a source of hope for regeneration (Boon, 2013: 86). This statement is where I rest. The vulnerability that I express throughout this dissertation is to (re)imagine, as Boon (2013) states, the relationship between the Self and the experiences that leave feelings of vulnerability, longing and stigma, long after they have happened. The relationship between the Self and the Other, that is, the things that happen, as well as what Cixous refers to as *entredeux* - the space inbetween, an opening to the self. In chapter one of *Undoing Gender*, Judith Butler (2004) has articulated such a positioning as being "beside oneself" —an openness to the other that effectively undoes the Self. In the process, a person does not always stay intact. Butler further asks in *Precarious Life*, Who 'am' I without the person? (Butler, 2006). Suggesting that there is practically no one without the other, which in this case illustrates that there is no Self without the Other, that is, no (re)imagining of the Self without the Other, no vulnerability without the stigma, no Siwongiwe without Arthur.

Christopher Slobogin, wrote an essay on mental illness and the death penalty in response to the Californian Supreme Court's decision to prohibit any children or people with mental illnesses to be executed (Slobogin 2000, 667). Slobogin's (2000) USA-based research and essay illustrates the USA's view of mental illness in the legal context and in the state of Florida where it is based, we are shown an exemplar of the West's view of mental illness. He states that medieval theory thought mental disability to be the product of possession by evil spirits and this stigmatising discourse finds its modern expression in the accepted perception that the "crazy" (one of the derogatory descriptors of mentally disabled people) are very different from the rest of us and are generally to be avoided.

Stigma functions on the premise that the stigmatised deviates from the norms of the stigmatisers (Yang *et al.*, 2014). There exist a set of cultural and social expectations that the stigmatised will have to fulfil to determine the density of the stigma. For example, if Arthur had children and a wife - having the identities of father and husband – it would have humanised him in ways that would lessen the social and cultural sanctions brought on by the stigma surrounding mental disability. It is also necessary to note that these nuances and complexities depend on the stigmatised person with a mental disability existing within a community of supposedly able-bodied people who do not have a visible mental disability. The trope of “us versus him” in alignment with the ease of, simply put, blaming bad things that happen in the community on Arthur, not only absolves the community of pointing out the actual problem. Which is gender-based violence, rape culture, misogyny and many other ills and crimes that are perpetrated on women and girls. It also perpetuates the argument brought forth by Yang *et al.*, (2014) that stigma is a moral experience which relies on the perspective and expectations of the stigmatisers within the community. This is akin to Pecosolido’s (2013) argument that an absence of factuality that often comes with face-to-face interactions is needed for stigma to be maintained. According to the World Health Organisation’s 1976 document on mental health care in South Africa, Black mental patients experienced social exclusion (WHO, 1976). There was not a single Black psychiatrist in South Africa at the time of this WHO (1976) publication, and vital decisions about thousands of African mental patients were made by white part-time physicians. In 2018 there were only 850 psychiatrists in South Africa for the entire population, which did not account for race. These social and political conditions engineered by apartheid went into producing stigma and producing the conditions for someone like Arthur being in the streets.

Arthur, like other Black people with mental illnesses became a placeholder for the dangers of the night, the township and the consequences of wandering about alone. Those allegations are a result of stigma and discrimination against people who are perceived to be against the norm of being able-bodied. Arthur was often called derogatory names that meant having a mental illness. Arthur, who had a mental illness which likely did not allow him to groom his hair and take very little care of his appearance, scared and followed young children around, was a marker of the age-old stigma that surrounded mental illness and intellectual disability. South Africa has some of the highest numbers of gender-based violence in the world. It is clear that

Arthur stood as a regulatory mechanism and a scapegoat for the ills perpetrated by able-bodied men. Arthur absolved these supposedly normal men and was used to regulate the ways in which women and girls moved around men in the township.

## **Conclusion**

The history of Arthur, the old man from my childhood bearing close ties with Arthur, the wheelchair is not only an account of how stigma, re-enforced and perpetuated by a community, can permanently be etched in a member of that community. It is also a story of how the trajectory of my life as able-bodied, disabled with a walking stick and disabled in a wheelchair makes stigma look and feel different. More accurately, how ableism manifests differently depending on your context or positionality. As much as the naming of my assistive devices represents me and my psyche, it is also a reflection of the ways in which stigma functions within the confines of that psyche. As an anthropologist, though, I am deeply concerned with understanding the affective and social forces that go into stigma as a social condition. The unpacking of the psyche, illustrating the social dimensions of the psyche, that my fears come from the way in which the community produced Arthur as a figure. Additionally, the vulnerability that the understanding of the aforementioned affective forces propels one into considering the extent of ableism being internalised, because Arthur was a mentally disabled man that I feared and stayed away from, but an assistive device meant to make the world accessible reminded me directly of him. This affective component seeps into my experience of bureaucracy as not merely an administrative phenomenon, but a social aspect where disability is concerned. The chapter that follows discusses how navigating what would be ordinary spaces subjects me to surveillance and forms of gatekeeping by individuals within institutions whose expectations I am beholden to.

## **Chapter 2: *Alls My Life I Has to Fight***

The title of this chapter, “Alls my life I has to fight” comes from a scene in the 1985 film adaptation of *The Color Purple*, a novel by Alice Walker. In the scene, an angry and crying Sofia, played by Oprah Winfrey delivers a monologue in African American Vernacular English to express her anger and frustration after a physical altercation with her husband, Harpo, where he tried to make her obey him. Her mouth quivers and widens and her breaths remain loud and short as she exhales, “Alls my life I has to fight, I has to fight my daddy, I has to fight my uncles, I has to fight my brothers! Girl child ain’t safe in a world full of mens. And I ain’t never thought I’d have to fights in my own house”. The first part of her monologue has made its way into social media memes and my repertoire, as I exclaim it every time that I encounter an inconvenience. The last sentence makes sense when I consider how bureaucracy affected me in my own residence. The film is not about disability but tells the story of diverse Black women who navigate their lives in the face of oppression and their experiences as Black women.

Bureaucracy, in my thesis, represents institutions of higher learning and the various gatekeeping mechanisms that are exercised and perpetuated by people in positions of power, such as the security guard. Participating in bureaucracy as a Black, queer, disabled woman feels like a fight – a tedious and daunting activity that you put a lot of energy into to get the desired outcome. This is part of the reason that Lewis Brown (2015) refers to participating in bureaucracy as a disabled person as a process. Sofia’s monologue goes on to mention the male relatives that she has had to fight (perhaps both figuratively and literally, the former alluding to the systems brought on by men), which leads me to interrogate two things. The first one is the oppressive systems that the men that I encounter perpetuate, one of them being a security guard at my university residence. In addition to that, the concept of intersectionality (Crenshaw, 1989) provides tools for understanding the unique ways in which my experiences are shaped, as my identities overlap with my disability. The second thing is the figurative and non-physical fights that I have had within my own home and family against the backdrop of my other identities of Black and queer, as my Cerebellar Ataxia is a condition that I inherited from my paternal side. This chapter explores how bureaucracy and intersectionality intersect with ableism in my everyday lived experiences.

*“But you don’t look disabled”*

*This sentence is one that I have become all too familiar with. Its pulse was even stronger when I had just been diagnosed – right before I started using Mantoa. My physical condition had deteriorated enough for me to be noticeably unsteady on my feet, but not enough to be fully dependent on a walking stick. Much as an umbrella or a beach hat has its occasions, Mantoa too had occasions where it was appropriate to accompany me where she was needed the most. In those days, I wasn't known as the girl with the purple walking stick yet. My embodied difference from my peers would later be correlated with Mantoa, who would be a representation of my own difference. Having become the mark of my disability, Mantoa was a potent embodied difference that warranted looking at.*

*In conversations with people who share my culture, I feel a sense of separation when I am viewed as strange or some sort of abnormality. For people with disabilities, who rely on artificial devices in their daily lives, the prosthesis has been a useful tool for defining their identities (Jain, 1999). It is possible for people with disabilities to engage in their world with these devices, enabling them to enjoy as much independence as possible. People with disabilities tend to be alienated in an ableist society that revolves around a sense of normalcy. As someone with a disability, self-identity has become an extraordinarily complex and profound concept, especially when you are labelled with the same set of characteristics as other people.*

*When I heard the sentence that I didn't "look" disabled again, I had just moved into my new residence in 2020 at the University of Cape Town. I was waiting in the reception area for a security guard to open the accessible entrance. Next to it were two turnstiles, which were not accessible. A tall, thin, middle-aged Xhosa man with an intimidating voice approached me. Important to note is that Mantoa did not accompany me at that moment. In the absence of her, I had no identifiable features that indicated that I had a disability and needed to use the accessible entrance. I was familiar with this man from previous encounters. I had met him before (with Mantoa). In our encounter, he made it clear that he was dissatisfied with my failure to say 'hello' and ask with a smile. From his point of view, he was entitled to these benefits in exchange for his assistance.*

This occurrence can be interrogated, analysed, and critiqued through the social identities that are possessed by both me and the security guard. The security guard is a perpetuator of bureaucracy by using his position in the university's administration to assert power. To be specific, we are both Xhosa, but I am a woman, and he is a man. He is middle-aged and I am

in my twenties. He is visibly able-bodied, and I am disabled. My experiences of bureaucracy, which is that the security guard was the representative of an institution and was invested with power by institutional bureaucracy, then, are altered by the social factors that reside in me.

Systems of oppression overlap and turn into new experiences. This suggests that stigma and discrimination lay the foundation of bureaucracy. Brown (2017) states that – what causes the experience to become increasingly distinct, as intersectionality highlights – stigma and discrimination can be considered social stressors. Discrimination and stigma within bureaucracy accelerate and amplify the angst of social interactions. In this way, mental health issues become synonymous with bureaucracy (Brown, 2017). This is in alignment with the idea that I included in the first chapter where I spoke of vulnerability and experiences of ableism being better understood through an affective lens. In terms of disability studies in general, as far as physical disability is concerned, not much attention has been paid to the question of whether such stressors help explain the mental health effects of functional limitation severity. There is evidently a greater emphasis placed on visible limitations than on invisible or unacknowledged barriers (Brown, 2017). In the incident above it could simply be “but there is an accessible gate” rather than questioning the unspoken and unwritten expectations of performance from me that make the process bureaucratic and difficult. Having to perform not only niceness and politeness, but also disability by highlighting my assistive device, which is highlighting that I do indeed need the access. I was expected to smile and say 'hello' to the security guard before asking him to open the accessible entrance for me. If I did not do this and ask politely, he was no longer just a security guard employed by the University to press the button and open the entrance, but an elder that I would be disrespecting if I disregard the process.

The intergenerational aspect between me and the security guard means that there are social cues and expectations of me – and him to a small degree – in our interactions. Expectations such as having to greet him as my elder and address him as my father, "Tata". Brown's (2015) emphasis on the mental health component that is cause and effect to the stressors brought on by bureaucracy describes it as a process that relies on the person on the receiving end to lessen the social stress brought on by the bureaucracy. McClure's (2019) contribution to this conversation is not fundamentally rooted in disability, but speaks to a phenomenon that is evident as far as

intersectionality is concerned. Microaggressions, according to McClure (2019) are shown by expecting women to show unconditional politeness and friendliness in public spaces regardless of whether a man meant well. Women should not be expected to contribute to a man's enjoyment or pleasure, especially if the men are employed to provide assistance.

*After making me wait until he was satisfied with my performance, the security guard pressed the button, and I walked in. Having to go to the grocery store, I made my way back to the reception area. Mantoa was with me when I returned to the reception area, and I greeted him. I smiled (even though I did not feel like it), and as I waited for him to let me through the access gate, he said, "but why don't you use the turnstile like everyone else?" I frowned and I simply gestured for him to look at Mantoa. At that point, I quickly found myself immersed in a reality that was split in two. On the one hand, even though I am disabled, I did not appear disabled. While on the other hand, I knew that looking disabled was somehow more palatable to get the recognition and assistance we need as disabled people.*

To receive assistance from people such as the security guard, I cannot be defensive or disagreeable. My response cannot be confrontational. Every interaction I have with a person would be extremely difficult and uncomfortable if I were to defend my dignity. I use a great deal of self-control to hold back the anger and frustration I feel when I am subjected to institutionalised gatekeeping by having to explain that I am not able to use the same facilities that able-bodied people can. Thus, it becomes an ongoing internal battle that I have to endure for the rest of my life. This is an example of the invisible limitations and barriers that ableism produces in the name of bureaucracy. Bureaucracy is thought of as an administrative procedure, yes, however it also entails embodied processes in which the difficulty to navigate and participate has an affective aspect to it that is detrimental to mental health and described as a stressor.

In their work, *Disability as Masquerade* (2004), Tobin Siebers reflects on navigating public space while using an assistive device. What I locate in this account by Siebers (2004) is a similar expectation to participate in a social interaction where one is "disabled enough" for the provider of the service to offer it. It reiterates the experience of assistive devices governing our

social interactions, but also how mundane exchanges with strangers who have the power can be, as defined in this chapter, bureaucratic.

### **“Looking” disabled**

In spaces where someone else is in charge of the needs of the disabled person, it adds an unnecessarily tedious component to participating in bureaucracy. Specifically, institutions that require supposedly impartial strangers who act out a professional role to have the right to give or withhold access. Tom Shakespeare (2000) frames the aforementioned as prioritisation. Shakespeare (2000) elaborates further that there are social situations in which ending social exclusion, for example, comes higher up the list of needs, than campaigning for not having to perform politeness, because you do not “look” disabled to someone else.

The idea of "crossing-over" and "passing" came to mind when I realised that having Mantoa occasionally made life and bureaucracy more difficult since I do not "look" disabled without her. Because crossing-over accounts for being pushed into making the decision to “look” visibly disabled in certain contexts. A decision which I made when I was questioned about looking disabled. Similar to passing, which is ““a cultural performance whereby one member of a defined social group masquerades as another” in order to enjoy the privileges afforded to the dominant group’ (Crutchfield, 1995 in Cooper, 2020). Melanie Suchet’s (2011) paper on transgender identity and crossing over within the trans experience, eloquently articulates the instance of having an assistive device on your body and how that then, in turn, makes your body something that identifies and others you. This is an occurrence that Tobin Siebers (2004) attempts to articulate when he informs readers that he exaggerated his disability and performed it so that the border between appearing able-bodied and disabled disappears. The performance of disability secures assistance from the agents of bureaucracy or gatekeepers and also recognition of disability but also the stigma of disability. Suchet (2011) does this by stating that the body presents as a vessel for that which cannot be spoken. In cases such as this where an assistive device accompanies the body, it amplifies the body as an unspoken vessel and, in turn, stands as an important characteristic for passing and crossing-over.

In the previous chapter, I spoke about how assistive devices become markers for disability. Cooper (2020, 60) frames this phenomenon as an “experience of the double-ness of the gaze” in which the disabled body is viewed in relation to other, able-bodied people. Consequently, a disabled person living in a world where everyone is seemingly perfect and fully human is difficult to reconcile. In addition to that, disability is often viewed as a fixed identity and an assistive device re-enforces its permanence. Therefore, when the question of “why don’t you use the turnstile like everyone else?” was asked, it led me to make the decision to permanently use my assistive device to eliminate tension for the gazer or person providing the service. This performing of one’s disability in exchange for service was evident, too, in Tobin Siebers (2004) saying that they will be using a wheelchair soon. Cooper (2020, 60) further posits that the disabled person finds themselves in a moment where they relinquish all their other identities. In those instances, it does not matter whether I’m queer or Xhosa or who my ancestors are. What matters is that I “look” disabled enough for that identity to be validated by the able-bodied person that I am interacting with. In this way, the world is different with and without Mantoa and different without.

Rosemary Garland Thompson’s *Staring: How We Look* (2009) unpacks staring and its impact on the disabled body. She goes beyond it merely being about curiosity and conceptualises it as an “inquisitive itch with many possibilities” (2009, 3). Staring can be used to interrogate contemporary issues in ways broader than intended or imagined (Garland Thompson, 2009). Carlyle (1988) states that “visuality” is the cultural practices and values connected with vision. Garland Thompson (2009) then explains that the curiosity of the starrer can evoke a reaction from the one being stared at, which ultimately makes the visual a profoundly social phenomenon. Both Carlyle (1988) and Garland Thompson (2009) account for how the individual’s “visuality” or stare is shaped by their cultural values.

The social model of disability, plays a significant role in understanding how both the security guard and I experience this idea of visualisation differently and how these differences add or take away from our interactions with each other. Because, in terms of bureaucracy one of the first things the security guard did was see me (gaze and visualise) and project his perceptions and opinions of disability onto me. This, in turn, made me have to make his visualisations more comfortable by having to “look” disabled enough for him to provide the services to me with

less difficulty. Bureaucracy, which I have shown to manifest through people in positions of power employed by the University, then becomes about security and surveillance. The security guard's ideas of surveillance link to a justification for him to look, surveil and make demands in the name of security based on his personal judgement and his viewing practices. In this way, persons with disabilities are often excluded from accessing social spaces and all of the benefits and resources that they provide. Thus, security means an experience of the social world where, as a Black disabled person, one feels insecure rather than secure.

Performative politeness and benevolence, for example, can be interpreted as the able-bodied gazer overcompensating for what they think that the disabled person lacks. This is a symptom of ableism or one of the ways that it manifests. I sometimes think that performative politeness is better than blatant disregard, and sometimes not. It is subjective, nuanced, and unique to every situation. After the incident with the security guard, going out in public and being comfortable presenting this identity to the world took courage. Being courageous is imperatively necessary, especially when coming to terms with a disabled identity while being subjected to a continuum of such events. Additionally, the incident with the security guard is sedimented by someone who literally is the guardian between inside and outside, and who I must pass to get to my home. It is not only physical limitations that restrict me to my home, but also the knowledge that each entry into the public world will be dominated by stares and by hostility. Institutions become more and more about the hostility of public space which is concretised by interactions with people who have even small measures of power like the security guard.

### **My experience of intersectionality**

It would be a disservice to intersectionality to think of intersectionality as simply “if not ableism then racism”. A necessary tool brought on by intersectionality is to realise that my disability adds another layer of oppression and discrimination to the sexism and ableism I was subjected to, creating a new and distinct experience that the security guard subjected me to. Erevelles and Minear's (2010) *Unspeakable Offenses: Untangling Race and Disability in Intersectionality Discourse* describes how Critical Race Feminist Theory approaches disability as an expression of intersectional identity wherein devalued social characteristics compound stigma. Intersectionality addresses a central feminist concern about capturing multiple positionalities,

placing an explicit focus on differences among social groups. The security guard has the power to perpetuate ableism and sexism that intersects with ableism. Our classes may be different too. Perhaps, in a nuanced and complex way, my access to education at UCT, access to that specific living space, access to Cape Town, or access, in general, may make him envious of me. My being disabled adds a thicker layer of envy that my pursuing a postgraduate education presented as I upend his ideas about people with disability being inferior or subjects of charity and not educated. Further in this chapter I spoke of the security guard and me both being Xhosa and how that came with the expectation of being on the receiving end of his *ubuntu*<sup>1</sup> for me, however, I quickly identified that *ubuntu* can be exclusionary, as it relies on who the person considers worthy of being considered human. Which was not for me.

For me, however the act of humanising myself is entangled with multiple, complex, intersecting oppressions. To clarify, identity labels do not fully encompass the multi-layeredness and nuance of me as a human being with those identities. The nuanced reality of my being a Black queer disabled woman means unpacking every one of the aforementioned identities and unpacking their complexities. As you are aware, my disability does not bound me to a wheelchair, as there is a wide range of disability. My Blackness is fluent in Afrikaans<sup>2</sup>, I am a Black woman who presents little to no femininity, my queerness is not characterised by a story of “~~corrective~~” hate rape<sup>3</sup>. Sofia from The Color Purple film’s “*Alls my life I has to fight*” resonates even more now as I write this, as it eloquently and accurately articulates having to navigate life amidst systems of oppression. Furthermore, Sofia mentions the men in her life whom she had to fight and later realises that she would have to fight in her own home (against the husband whom she chose). In thinking about how I inherited my Ataxia from my paternal side, I feel anger and resentment because I wonder why I was chosen out of all my father's children to carry this gene, which further stigmatises disability. Lastly, my feelings about the incidents at my residence (my home away from home) are similar to Sofia's shock at having to "fight" at home.

---

<sup>1</sup> A Nguni word for the quality that includes the essential human virtues of compassion and humanity.

<sup>2</sup> The language of Afrikaans in South Africa has violent connotations for Black South Africans. During apartheid Black people were forced to learn in it and speak it, and it is thus worth noting when a Black South African is fluent in Afrikaans.

<sup>3</sup> In the dynamics of this form of genderbased violence against queer Black women, referring to the rape of lesbians as corrective rape is heteronormative and re-enforces that queer people are to be corrected. A lot of work has been done to change it to hate rape or homophobic rape.

It is common for disabled people to internalise ableist ideas when people and institutions around them pressure them to hide and minimise the impact of their disability. The act of passing takes an emotional toll on disabled individuals, who experience loss of community, anxiety, and self-doubt as a result. I have experienced and framed passing, in this chapter, as the relinquishing or minimising of one identity to make it easier to navigate the world. Intersectionality allows for an understanding of how identities like being Black, being a woman and disabled can coexist.

The security guard's questions for me became a questioning of my existence and my position. To explain, "why don't you just use the turnstile like everyone else?" also landed as "why do you want to be treated differently from other students here if you're just like them?" and, my favourite, "but you don't look disabled" lands as "you don't look the way I think people who deserve these services should". These questions, in my view, should not exist, because I am a disabled human being who is entitled to the access, no matter what.

## **Conclusion**

This chapter began with using to fight as a synonym for navigating bureaucracy that is instantiated by people like the security guard at my residence, who form part of public life and institutionalisation. Fighting can stand as a description of what it means to exist in the context of oppressive systems. With the security guard, I illustrated how an institution's rules can be used by someone in a position of power to increase difficulty. Additionally, the oppression and discrimination that I experience are not only due to ableism, but also my other identities of being a Black queer woman and how those overlap. Intersectionality teaches us that all oppression is linked and the overlapping of identities such as mine create a distinct and unique experience of oppression and bureaucracy. Bureaucracy as rules means that some rules that have been put in place by an institutional bureaucracy falls short, because individuals enact power based on looking that is riven with intersectional oppression. Bureaucracy, then, becomes a process that is layered in difficulty and the disabled person participating in institutions often has to make a decision of compartmentalising one identity as important over another one or two identities to remove a layer of difficulty. This is characterized as crossing-over or passing. The next chapter focuses on desirability, dating while disabled and stigma.

### **Chapter 3: Dating and Stigma: On care and desirability while disabled**

Disabled people have long been viewed as asexual people who offer little to society except for requiring care and being fully dependent on able-bodied people (Addlakha, Price, Heidari, 2017). Nuanced conceptualisations around care and desirability in the context of disability and dating allow critiquing of disability in much more extensive ways. This chapter aims to untangle ideas about care and desirability in the lives of disabled people and how those ideas manifest in the perceptions of disabled people in romantic settings.

Furthermore, this chapter explores movement and the politics of movement for disabled people. This conversation illustrates that not only is movement, the act of moving a simple idea, but an equally nuanced political reality for examining the social interactions of disabled people. Tobin Siebers' (2013) theory of complex embodiment provides tools to understand and unpack the subtle occurrences and meanings in my interactions with someone I lived in residence with, Nomuzi. She was a tall, full-figured woman with a deep and loud voice whom I often saw wearing pink scrubs. Nomuzi showed me that there are subtle ways that being accommodative is entangled with dating. These subtleties are synonymous with the social cues that emerge from interacting with a social group you feel comfortable with, and how those cues manifest in dating.

*In the residence an average of ten people would share a kitchen. This meant that even though everyone had their own room there were a few strangers that you would share space with sometimes. This is where I met one of my participants, Nomuzi, who told me she was deaf in one ear. She had no hearing aid or marker of her impairment. The social model of disability says that assistive devices shape the social experience of a disabled person, as they are for the individual, but shape the social experience (Ripat & Woodgate, 2011). Thus, assistive devices like a hearing aid introduce her as disabled, without her having to say it. I pulled out a chair from the round communal kitchen table to sit, exhausted from academic toiling, released Mantoa from my right arm and rested the part of her that I grip with my hand on my thigh. It was only when I looked up that I noticed how Nomuzi had turned her head sideways so that her ear could face me. Her movement introduced her and not her hearing aid, in this case. Having a consciousness of the notion that different bodies have different abilities, I did not ask why. When she asked me what I was doing my Master's in and I answered, "Anthropology.*

*Disability and stuff”, she then told me about her ear.*

The social model and the medical model of disability are an enlightening foundation for understanding the distinction between impairment and disability. The social model and medical model of disability referring to the ways that society’s (in)accessibility can govern a disabled person’s social experience (Shakespeare, 2006). The medical model of disability, on the other hand, is limited to diagnoses and impairment (Shakespeare, 2006). I had not imagined impairment and disability could collide or even co-exist. By this I mean that Nomuzi’s deafness did not necessarily mean that she was part of Deaf culture or even disability culture. Unlike me. This became more apparent when she said that she did not consider herself disabled. As Penn (1993) suggests, Deaf people consider being deaf a social identity, rather than a disability. Accompanying the value of hindsight and reflexivity, I realised that there was a layer to this situation that I did not see instantly. I wondered, at first, where “not considering herself disabled” came from and if her personal view of disability had an influence on that. I became keen on knowing about the impact adjusting her head when engaging in social interactions had on her, primarily within the dating sphere.

## **Movement**

For many years, since the inception of disability theory, the social model of disability has been the foundation from which disabled people have attempted to organise and categorise themselves (Oliver, 1997). This has resulted in an immense evolution and success in disabled people’s autonomy and their rethinking of their position in society. Michael Ralph’s (2012) offering to *The Disability Quarterly* critiques the idea of movement and that our environment amplifies or restructures movement. This, as a result, makes movement political (Ralph, 2012, 2). Important to point out, however, is the fact that movement is not a metaphor for social organisation nor is it a shaper of socio-political life. But rather the body simply moving. The word “movement”, Ralph (2012) articulates, has a political aspect that tends to be associated with “social movement politics” and with a prospect for social justice.

Tobin Siebers' (2013) idea of complex embodiment allows for thinking about movement and the politics thereof in ways that do not limit us to a single aspect thereof. A few years prior, Siebers' (2008) article, *A Culture for Disabled People* states that disability pushes individuals

to find other areas of the body to do things. This others disabled people from able-bodied, normative social interactions. And, on the other hand, forms kinship with other disabled people, as we move differently to perform tasks. Like in the instance of Nomuzi, the movements we both respectively made illustrated a nuanced and complex manner of using our respective bodies. Furthermore, us using our bodies in these unique ways accounts for the complexity of the social experience of disabled bodies. This scepticism is displayed by the views held by Nomuzi of not identifying with the label disabled and the complexities that accompany claiming that identity. Capital D, Deaf refers to people who are recognised as part of the Deaf community; while small d deaf refers to people unable to hear (Golos, Moses, Wolbers, 2012).

Siebers' theory of complex embodiment (2013, 279) accounts for people's perceptions of their bodies as contradictions. One of these contradictions being that modern culture perpetuates the idea of the "perfect" body, when, in fact, human life is not made up of the body alone. Bodies, as Siebers' (2013) suggests, are thought to house the soul of the human, which exists in an environment that in turn shapes the ideology of the human which does not permit the thought of contradiction and what it offers to question disability and impairment (Siebers, 2013: 280). It places opposites together, that two truths can exist simultaneously, for example, that having the identity of disabled does not mean forfeiting the identity of human. Or that having the identity of disabled and choosing to live at a certain residence does not mean its accessibility is perfect, whole and not open to critique. In this way, opposites or contradictions turn into complements of each other (Siebers, 2013: 280). The following excerpt highlighted the scepticism and criticism of the way that disability is perceived even and discussed if they were signed up with the university Disability Services.

*"...so yeah, I don't think the Disability Service can do anything for me."*

*"Why is that?"*

*"They provide things like transport, which I don't need, 'cause my legs work. And maybe hearing aids, but I already have one, so what could they do for me?"*

Nomuzi is not registered with the Disability Service (DS), as she does not see the necessity or need to be. Additionally, entities that provide this kind of support for disabled students and people at large tend to, erroneously, have a one-size-fits-all approach to their services and support. Although this is evident in the sentiments of Nomuzi, the DS does, however, provide

for the needs of different students and their different disabilities. Such as providing scribes for Deaf students. This is not to say that these organisations ought to register and support students with disabilities anticipating that they are going to go from needing only a hearing aid to eventually needing a wheelchair and transport, as well, but at least frame their own views on disability beyond the cared-and-caregiver binary. The view of disabled people as in need often causes difficulty to view them as something else and when this happens the cared-and-caregiver relationship creates a binary that often cannot be seen beyond.

Kroger (2009) posits that the idea of care in the context of disabled people consists of and is reliant on the view that disabled people are dependent, non-autonomous second-class citizens (Kroger, 2009). Kroger's (2009, 398) critique of care propels us into considering that care has come to mean not caring about the human being. But caring for the experience of taking responsibility for that person. Furthermore, as per Kroger (2009, 399) people who require care are said to be unable to exert choice or power, which extends into the view that disabled people (who require care) are helpless and powerless. Everyone needs some form of care, because everyone's needs are different. However, the view that Nomuzi has of disability and aligning with an organisation that offers support for the disabled is akin to the aforementioned view of care for disabled people. That is, that requiring care makes you inferior, less desirable or even a sign of failure. By extension, not wanting to be affiliated with the DS means that she associates the support and, well, care that they provide with the relinquishing of power, which may or may not extend into her not wanting to label herself disabled.

When I was given the wheelchair by the DS that was shoddy, unkempt and then named it after Arthur, a mentally disabled man from my childhood that I stayed away from, I was unconsciously being steered by that intersection. This allowed me to identify and name my very own internalised ableism and stigma. In Nomuzi's case, too, stigma and ableism are internalised, as they are a consequence of one's history, environment and psyche. It can be deduced from her view of not only herself, but the DS and what it would mean for her to be registered with the DS. What can also be deduced is that Nomuzi subscribes to a politics of disability that refuses to see impairment as disability. This is valid, but I would argue that internalised ableism cannot be erased from that.

For a long time, people with disabilities have been pitied by people who do not have disabilities (Hunt, Swartz, Carew, Braathen, Chiwaula, Rohleder, 2018). This view exists even among able-bodied people who live in the same communities as disabled people, which pokes holes in Pecosolido's (2013) theory that the stigma held about disabled people by able-bodied people relies on the absence of proximity and closeness. Someone can be close to disability themselves and still stigmatise themselves. We see that in relations as intimate and as close as romantic relationships, as where desirability is at play it relies on intimacy and closeness or, at least has intimacy and closeness as a goal (Hunt *et al.*, 2018). Desirability, in this instance, means being attractive to someone. This chapter illustrates that desirability does not only apply to romantic relationships, but friendships as well. Desirability is directly linked to beauty standards that are systemically embedded in our daily lives, where the more desirable you are, the more flexible the capacity to be cared for. The white, heterosexual male with perfect symmetry who is able-bodied has systemically been presented as the standard for the human.

Hunt *et al.*'s (2018) study where they interviewed able-bodied South Africans on dating disabled people. The interviewed stated that a large portion of their opinions were manifestations of pity and condescension. An instance where this observation was apparent was when one of Hunt *et al.*'s (2018) participants stated that they would not want to offend the disabled person asking them on a date by saying no, so they would say yes to a date with them. This aligns with Kroger's (2009, 398) point that disabled people often get pitied. Fortunately, though, it is "often" and not "always". There are many instances where care is genuine within interabled romantic situations.

When I noticed that Nomuzi turns her head to a certain side, I asked her how it affects, if at all, how she goes about walking with another person.

*"I automatically walk on people's right side so that my left ear can be right next to them, and I can hear them better."*

*"What would happen in a situation where you walk with me, for instance, because I use Mantoa on my right side and cannot have someone be on my left in case they trip."*

*"I would just accommodate you, so you don't feel offended and ask you to keep repeating what you say. But if I am wearing my hearing aid it wouldn't be a problem..."*

*I've always seen it as, I'm willing to adapt to my surroundings."*

*"I see. Do you date?"*

*"I have" (laughs)*

*"Would you date someone who is disabled?"*

*"It's easy for me to say 'yes', but I don't know. Because of what I study I have worked with people and seen that you can use this to help with that, so."*

On the question of being accommodative and what that may look like at the intersection of impairment, disability, social identity, care and ableism. Hunt *et al.* (2018) posited that "not wanting to offend" is a ramification of the pity that able-bodied people feel towards disabled people and that the care that they exhibit, according to Kroger (2009) rests in obligation. I would, then, argue that although Nomuzi admitted to being disabled, she still has a resistance to it and keeps it at arm's length enough to inhibit opinions and actions that ultimately show two things. Firstly, that she behaves similarly to how I did in not wanting to create conflict with the security guard, in the previous chapter, so I smile. Secondly, she is engaging in an act of care for the other person. Which is perhaps a limited form of agency but a way that disabled people can exert some control over an encounter by being accommodating, even if it is not necessarily fair. Here we are shown the ways in which one's own bodily difference enforces an openness and flexibility to other bodily differences. Nomuzi's consideration, understanding or consciousness of bodily differences and care is a ramification of experiencing the system of ableism or at least knowing that it exists and having seen others be subjected to it (Van der Heijden & Haries, 2018).

### ***Disclosing and dating***

What follows is an account of one of the many experiences that I had with (online) dating while disabled, which set the blueprint, so to speak, of my experiences and views of dating and desirability.

*Any online dating sites that I have been on in the past five years have never said "disabled" in the About Me section. Before Mantoa came into my life when my Ataxia was still "mild", there was no reason to, as there simply was no assistive device. After having matched with someone, a woman, who liked my profile back and exchanging witty texts, and eventually the inevitable*

*“let’s meet up. On which day are you free?” came up along with anxiety. Anxiety because I no longer had just my witty personality and cute photographs to rely on, I had a physical presence that was required to keep the interest of the other person. On one occasion, pre-Mantua, but post-Ataxia, I decided to tell the person of interest that I was totally on board with meeting up, but they needed to know that I had “a condition that made me a bit unsteady and unable to take the stairs”. The person of interest apologised, wanted to know more and vowed to “carry me up and down the stairs”.*

*We met for ice cream at a McDonald’s in Braamfontein, Johannesburg. When she saw me enter, she bolted for the door to take my hand to help me over the step that led to the sitting area. I am not certain if that was due to the woman’s version of chivalry that she wanted to show me or if she wanted to show me that she could keep her word or if she thought that that is what was expected of her as someone who was on a date with someone who had said that she had a particular ailment and required that type of assistance.*

*But what I am certain of is that that set the precedent for the duration of our relationship. “So it’s gonna get worse?” she asked and I not having had the knowledge and experience that I do now, simply said that I did not know. “Google said it is”, she said, which was news to me because I refused to entertain the diagnosis. We spent hours chatting on that Monday and by Wednesday, in true lesbian fashion, we were in an exclusive relationship.*

*Our relationship lasted for three months, and in the last few weeks she went M.I.A. without a word. She later told me that the reason she had been M.I.A. was because she could not bear the pressure of “having to take care of me”. Because I was in my infancy in my disability and had an elementary understanding of stigma, I was the one who apologised to her and begged for another chance, but I left Johannesburg and the relationship ended.*

What this vignette illustrates is that there is a relationship between care and desirability. Dating a person with a disability can bring forth ideas of interdependence as burdensome and ultimately taking away from the possible romance and intimacy. The romantic prospect mentioned above initially viewed my disability as an unusual, new, perhaps even exciting, aspect to dating me before they met me and viewed my need for care as an intimacy that could be weaponised and heighten their appeal to me. However, as the relationship progressed my need for care became burdensome and they ghosted. This assumes that all people, even able-

bodied people, do not require some kind of care and assistance and it assumes that it is solely reserved for disabled people. In illustrating that two things can be true at the same time, Siebers (2013) shows us that we cannot escape the fact that disabled people require care and support. The able-bodied romantic prospects/partners of disabled people who exhibit the accommodativeness of Nomuzi, as she equates dating someone who is disabled to entailing care, can result in seeing yourself as a caregiver more than a romantic partner. Nomuzi's assertion, analysed after the vignette above, evoked in me the idea that care was equated to being disabled. Which re-enforces a dehumanising lens, because everyone, disabled and able-bodied, requires some care. Attaching requiring care only to disability is equal to not being seen as fully human and feels much like rejection.

As Hunt *et al.*'s (2018) research report on the dating life of South Africans with and without disabilities reveals, disabled people are rarely viewed as potential romantic partners. Those sentiments are much more evident overall towards people with physical disabilities than those towards persons with less visible disabilities (Esmail *et al.*, 2010 in Hunt *et al.*, 2018). To reiterate, I had no assistive device at that point in time. All I had was a diagnosis and my daily lived experiences. The romantic interest and I had not physically met prior to the vignette, thus I would say that her only having her imagination may have amplified any curiosities about me that she had. Letting the person know before they meet me also ties into the fact that I was avoiding *the look* that I was used to getting when people saw me and saw that I was not the able-bodied person that they were expecting. Hunt *et al.* (2018) attribute this to being a form of disgust by stating that when some of the able-bodied participants in their research were asked about going on a date with a physically disabled person, some responses seemed to suggest powerful negative affect (Hunt *et al.* 2018).

This recoiling, revulsion and fear is what I interpret the look to be and what I attempted to avoid when I would disclose my disability to online suitors. The look is one I would describe as disappointment, because you are not what was expected. Not the norm. The look of recoiling, revulsion, fear and, to me, disappointment manifested as a cringe. Everything I was, thought of myself as, viewed of myself gets reduced to a look that I try to avoid at all costs as far as I can control. One of the ways I do this is by disclosing. Beyond it being an avoidance tactic, it is also a way to protect myself. Garland Thompson (2009: 3) conceptualises “the look” as an

“inquisitive itch with many pourabilities”, suggesting that, even without having experienced it yet, the mere anticipation of it is the same as opening an affective can of worms. Garland Thompson (2009: 9) dissects staring as a placeholder for revealing what hides in seemingly obvious visual gestures. The intentions, the feelings, the unspoken. Similarly, Cooper (2020) concludes that “the look” is something that made her, in that, her experience with being looked at and subjected to “the look” shaped who she currently is. Cooper (2020) adds that there is a profound relationship between being gazed upon as a disabled child and then as a disabled adult.

No one has ever come up to me in person and asked me to go on a date. I would like to believe that it has nothing to do with the fact that I am physically disabled and use assistive devices. People only ever come up to me in a supermarket to ask me if I need help or to give me unsolicited advice. As of 2022, I was in the second year of a romantic relationship with a nonbinary Occupational Therapist that I met on one of the popular dating applications. The way we met aligns with the pattern that I have noticed that my dating history shows that everyone that I have dated and become romantically involved with has met me online first, chatted with me, and liked my personality. When the question of meeting in person arises, I make the choice of whether or not to disclose.

The difference in events that I imagine in a world where someone would come up to me in a supermarket and ask me out versus the reality of meeting them online first is a difference that I can only observe as being brought on by my use of assistive devices. With my current partner, we chatted via text for a few weeks before we were both back in Cape Town and could meet. I let them know before meeting that I had Ataxia, because they told me that they were studying Occupational Therapy. This made me comfortable in the way that Nomuzi must have been when I told her that I was an anthropologist who was studying disability. The fact that they were in Occupational Therapy also made the care that they showed me sit comfortably with me and it was synonymous with the fact that I was simultaneously the subject of their desire. Care does not automatically show us ableism. It is often only upon further examination and a closer look that we are able to identify ableism within relations or performances of care. By this I mean, that using the example of me in a supermarket and having strangers offer to help me when I am merely existing, is an example of performative care that is synonymous with

ableism. But kindness? When someone is kind, in my view, it is more about the intention of the person and less about the performance of care.

## **Conclusion**

It is nearly impossible to speak of dating and desirability in the context of disability without speaking of stigma. Stigma is the overarching sensibility that governs the way we think of what makes someone dateable or not. When considering the dating realm, through concepts such as care and desirability, we are able to locate stigma in those relational states and use it to unpack how relationships unfold, how people characterise their willingness to be with someone who is disabled and their capacity to sustain the relationship in a way that does not feel demeaning or humiliating for the person with a disability. Furthermore, ideas of being human and ideas of personhood translate to an expectation that in dating and intimacy, one will be loved and cared for and humanised through that love and care. There is also the expectation that being humanised in that way would make your personhood flourish. Thus, the refusal of the able-bodied person to offer the disabled person care is a characteristic of not offering them full personhood and is dehumanising.

The power dynamic existing between the disabled, the able-bodied and, as in the case of Nomuzi, the person with the impairment who rejects the label disabled bears stigmatised views of disability to begin with. Stigma is evident even in the ways that we move, because physically disabled people often do things with their body to make performing tasks easier at times. In the absence of an assistive device, it can be a way to build kinship or the comfort of offering convenient adaptations to the other that I saw in the interaction with Nomuzi. Also, Nomuzi's refusal to associate with the Disability Service shows a rejection of the identity disabled and a refusal to be seen as requiring care. The stigma that we often internalise that disallows us to do what we usually do with our bodies, took a backseat, so to speak, in that moment and let her speak to me with comfort. This instance further prompts one into thinking of the concepts of movement and complex embodiment, as the social life of the disabled person is profoundly shaped by the level of comfort that governs the comfort that it takes to make a certain movement, or to move in a certain way. On subtle movement, the following chapter focuses on

community and how memories, behaviours and beliefs can be passed around through socialisation and time and manifest in how community members interact and practise *ubuntu*.

#### **Chapter 4: Community**

*On the 18<sup>th</sup> of April 2021 a fire started on Cape Town's Table Mountain. This fire burnt about 6000 hectares of the land on Table Mountain and spread onto some areas of UCT's Upper and Middle Campus, as well as some neighbouring buildings. The new residence that I had moved into a few weeks prior is in Observatory, Cape Town, a suburb close to UCT. The residence that I live in was affected by the smoke from the fire.*

*The residence has a capacity of an estimated 880 students and out of that 880, which is spread across seven floors, only seven rooms are accessible. Ergo, only a maximum of seven physically disabled people are able to live in the residence at any given time. The statistics that are shared below illustrate the reality of how under-represented disabled people are.*

*That night, a caregiver from the Disability Service (DS) phoned me, asking me to pack a bag including school essentials and meet in reception. I did so and met a few other disabled students. I saw someone with a wheelchair, another with crutches and the rest did not have any assistive devices. We were taken to a hotel in the city and the next day had lunch together in the hotel's restaurant. I sat at a table with Zikhona and Melikhaya and after introducing ourselves to one another, I was pleasantly surprised that no one asked the infamous and invasive "So, what happened to your leg?" question.*

The fire that took place in Cape Town in 2021 brought together a community of students who all sought refuge. As it should be, a community shares a common goal or interests, however, there are often members within a community who are not in alignment with the ideals and experiences of the community at large. The commonality that is assumed to be natural and automatic then goes away. This commonality often comes in the form of *ubuntu*, an African way of networking that is based on the awareness of shared humanity (Swartz, Mji, Gcaza, MacLachlan, Hutton, 2011) and in the different communities that I have been a part of throughout my life, it is clear that *ubuntu* can be exclusionary, violent and not this romantic idea that *ubuntu* is almost like a gene that all Black people are born with. This chapter discusses that, disabled members of Black communities still get subjected to stigma and various forms of exclusion that manifests in violent ways. In this chapter, Tatomkhulu, another disabled man from my childhood is compared to Arthur who I discussed in chapter one. What follows are statistics that show disabled people in higher education and as a disabled student who belongs to these communities myself, it is necessary to mention.

In the Department of Higher Education and Training's (hereafter DHET) *Strategic New Policy Framework on Disability*, a document released in March of 2018, the DHET acknowledges that there is a historical context to disability, as well as systemic, institutional and personal challenges that disabled people in the higher education system face (NPF, 2018). Within that acknowledgement, however, the document emphasises only making available the future statistics about disabled people in the higher education system with little to no record of existing statistics (NPF, 2018, 74). According to Stats SA's 2011 census on persons with disabilities, 7,5% of South Africans were disabled. Of that percentage, only 20% of tertiarygoing age (20-24) are enrolled in the higher/tertiary education system. The statistics of students with physical or disclosed disabilities in higher education in South Africa barely exist at only 1%.

As an involuntary product and resident of the ableist world, up until that point I had never "hung out" and shared a meal with other disabled people. Most strangers I encountered I met through another friend or acquaintance. The point is that none of them had visible physical impairments or disabilities. In the first few seconds of meeting the other people with disabilities I held my breath waiting for the moment where they would ask me anything to do with Mantoa or how I became disabled. Disability, however, was the last thing on their minds. I am not certain if it is because having a crutch is associated with a temporary injury or if they just did not encounter (enough) disabled people to be aware of upholding social etiquette amongst disabled people as well.

The expectation of invasive questions about my disability from able-bodied strangers is an occurrence that Nancy Weinberg (1983) labels a prime concern in the social experiences of disabled people. The impact of social inequities on the disabled person's life and the discomfort felt by the disabled person in public social situations may lead them to restrict their ventures in public, and thus seriously limiting their activities. What Weinberg (1983) barely accounts for, however, is that this is synonymous of the cycle of ableism that I mentioned in the first chapter. Kumari Campbell (2008) continually critiques interactions that contain these cycles of ableism and instances where able-bodied people are curious about disabled people's bodies and aids. According to Campbell (2008) these interactions as being void of illustrating that ableism is complex and not a single definition or experience. Further reading on how ableism can be

internalised, which was brought to the fore in the first chapter, we are shown that (internalised) ableism basically says that the more ableist the world is the less disabled people go outside (Campbell, 2008). What Weinberg (1983) does not acknowledge is that the integrity of the disabled person may be impugned by people who deny the disabled person the public respect that is given to able-bodied people.

It is only when I was around people who were also disabled and with visible assistive devices that introduce them to the world before they open their mouths – just like me – that I discovered that it was possible to meet strangers and not feel uncomfortable. Harriet Cooper (2020, 51) places affect at the centre of disabled people’s interactions with able-bodied people as well as disabled people’s interactions with other disabled people. For Cooper, the experience of being disabled is formed relationally, in and through an exchange of gaze. That is, how the disabled person feels about being looked at can reproduce an action or thought that shapes the interaction. In Chapter 3 I reflected on “the look” and how it is a point of discomfort. Additionally, anticipating, expecting and even experiencing “the look”, that is, to be looked at in a manner that forces the stigma held by the looker onto the disabled person, is a way for disabled people to curate our coming-and-going and who we get around. Once we are at the receiving end of “the look” or the gaze, it evokes a response in us which is often to look away. Rosemary Garland Thompson (2009) illustrates that staring is simple, complex, natural and unnatural simultaneously. Illustrating that both the gazer/starer and the one being gazed upon/stare experience a multitude of complex feelings that prompt an action such as looking away from the stare. Staring is more forceful than simply looking, Garland Thompson (2009, 9) continues, which alludes to why it evokes complex emotions and discomfort for the stare and staring has different meanings across cultures. One of the difficulties, of being on the receiving end of this type of gaze as the disabled person is having the onus brought onto you to respond to that gaze. Thus, with the guidance of Cooper (2020), it can be concluded that in order for awareness of one’s disability to exist one has to be aware of the existence of others and, therefore, how others will relate to you. In other words, I am because you are.

Being received without the invasive questions about my disability or my assistive devices by the other disabled people automatically made me remember how in the presence of able-bodied

people, the opposite happens. This experience of meeting other people with disabilities as a disabled adult contrasts with my staring of Tatomkhulu as an able-bodied child below.

### **Community in childhood**

What follows is an account of an encounter with my friend's disabled father as a young child and the ways in which my regard for him contrasts with Arthur.

*In the same area and during the same time that I encountered Arthur, one of my friends, Sibongile's father, had a wooden leg. She was three years older than I and lived in the same street. Her family was Xhosa, and just like mine, integrated into Tswana culture because of the Northern Cape township we were in. What often happens when people who have the same mother tongue find each other in a place where the dominant language of the demographic is not their own, they gravitate towards each other.*

*I referred to Sibongile's parents as 'tatomkhulu' and 'makhulu', which is Xhosa for 'grandfather' and 'grandmother' respectively, as her parents were old, her older siblings were closer to my mother in age, and she was born much later than her youngest sibling.*

*One day I was sitting in the living room of Sibongile's house waiting for her to finish a chore so that we could go outside to play. Her father, Tatomkhulu, went into the room that allowed anyone sitting in the living room visual access to the room, sat on a chair and began removing his shoes. His dark blue socks were next to be removed and as he rolled up the right leg of his black trousers, I stared in shock at what was under the leg of the trouser: a wooden prosthetic leg that he placed next to him and was left with only a stump from above his knee.*

*I had never seen anything like that before and looked away, pretending not to have seen what I had just seen. When Sibongile and I were outside playing I asked her what happened to her father's leg, and she responded with a story about how he used to work for a railway company and got injured by a train.*

Juxtaposing this story against the story of Arthur and what he represented and was a placeholder for, there are various realisations that one could come to about disability and community. Arthur and Tatomkhulu are the first disabled people that I encountered: one being mentally disabled

and the other physically disabled, respectively. Arthur, an unkempt, dirty public figure who became a synonym for what is bad and to be stayed away from. Arthur also had no family and was the community's boogie-man figure whilst Tatomkhulu, a father, a grandfather and husband who was physically disabled, was respected in the community.

When my friend pulled me aside to whisper the story of Tatomkhulu's prosthetic leg, this showed me that, in hindsight, disability was something to be kept quiet about. Tatomkhulu not looking disabled in public, that is, "passing" and my having to be in the privacy of his home to see that he indeed was disabled, further reinforced that in that community there is a difference between public and private disabled identity. Thus, a difference between Arthur and Tatomkhulu. What is important to note is that Tatomkhulu may not necessarily have been "hiding" his disability in public, but there was a huge cultural component to it. As a Xhosa man, there would not be an instance where Tatomkhulu would be in shorts in public. In addition to that, Tatomkhulu was a pastor and led church services which added to the respectability that was required for the kind of work that he did. Reynolds Whyte & Ingstad's (2007) declare that time of onset and social standing in the community have an impact on the experience of disability. As a pastor, Tatomkhulu had the responsibility of guiding people and ensuring that they remain within a certain type of behaviour. However, as a man he was not expected to be the primary caregiver and did not have a fear of Arthur embedded into his psyche.

Young girls and women were socialised into fearing Arthur, but not men. For women with disabilities who are mothers there is a heightened level of surveillance and scrutiny (Fredericks, 1987) which stigmatises them further. However, as a man, with high status, for Tatomkhulu his prosthetic leg provided him with an able-bodied identity in public that allowed him to retain the status and not be surveilled and scrutinized in the way that disabled women are. This aligns, too, with *ubuntu*, in that Tatomkhulu had already been humanised because of his position and thus *ubuntu* was extended to him.

## **Ubuntu**

A community is a place where humans of different social roles perform and fulfil those roles to relate to each other (Simpson, 2014, 19). This definition is extended into Berghs's (2017) and

Livingston's (2008) stance on human beings being human beings because they exist in relation to each other. Which is basically what a community is. Importantly, though, *ubuntu* can be exclusionary and violent, especially where a community is concerned. Community members like Arthur can be stigmatised and treated as outsiders to be feared. We need to be wary of only regarding *ubuntu* as a perfect and complete way of life that is free of stigma and other social systems that plague a community. It is better thought of as an aspiration. *Ubuntu* is shaped by the views, experiences and history of a person and community as a whole. Communities do not exist outside of oppressive systems such as GBV, which is what Arthur was a pariah of. The stay-away-from-Arthur-or-you-will-become-a-victim-of-GBV narrative refutes theorisations of *ubuntu* as a perfect circle that every Black person can draw.

*Ubuntu* is an African humanist and ethical worldview where disability, as part of a common humanity, is necessarily part of what makes us human. The expression '*umntu ngumuntu ngabantu*' is isiXhosa for, 'a person is a person through other persons' (Berghs, 2017, 3). It is astounding the number of white academics' works on the concept of *ubuntu* that are available in relation to the work of Black academics, however the idea that *ubuntu* presents Africans as a romantic and euphoric antithesis to white people in society can be an inaccurate representation of disabled Black people. *Ubuntu* forces one to have certain expectations of Black people and re-enforces stereotypes. As is what I experienced here, on one hand, because not every Black disabled person I met during the fire or that I had encountered all through my life was "nice" to me or displayed *ubuntu*. Even though Mji *et al.* (2010) mention that some argue that in Africa there may be a greater acceptance of diversity and social inclusiveness, and that Western concepts of disability that emphasise medical issues may be inadequate.

Berghs (2017) shows the intersections of the African context and disability to illustrate an African model of disability, that is, *ubuntu* ushers us into thinking seriously about a shared collective humanness or social ethic. Which means to examine how Africans have framed a consensus for this shared humanity (Berghs, 2017). *Ubuntu* dictates that disability is what makes us human. The awareness of disability and humanity exists amongst other disabled Africans, and they are, in turn, able to perpetuate it for this reason (Berghs, 2017). Again, this sentiment has many inaccuracies, because in this way neither ableism nor internalised ableism should exist, because life is a musical of pastel colours where we are all recognised as human

to the same extent. Furthermore, someone like Arthur would not be a pariah in the community if it were entirely true.

My interaction with Zikhona and Melikhaya, two Black disabled strangers was pleasant, respectful, joyful and, above all else, felt normal. Davis' (1997) theorisations of normalcy problematise the ways in which normalcy focuses on making the 'other' the problem (how disabled people are othered in the world) and argues for the recognition of what is 'other' to not be viewed as the problem. *Ubuntu*, can be perceived in the intricacies of social ethics and etiquette of and towards disabled Black people in society. It can be used as a pivotal tool for unpacking this pleasant surprise that I had when interacting with strangers who were disabled, while remaining a critique for this very interaction and similar interactions throughout my life. Berghs' (2017) articulation, of *ubuntu* is akin to making visible the invisible, which is to say that, in my view, the parts of oneself that are unseen and often secondary, that is, "I am because you are". There is not an "am" written on anyone's body for all to see. As the observer, there is something that ought to be recognised in you that prompts *ubuntu* to be given to you. Moreover, those identities that do not have an assistive device that the world can see, tie directly into the comfort and kinship that came with meeting disabled strangers and having a conversation with them where we were able to recognise each other's humanity in our shared disabled identity. In a further argument, Berghs (2017) argues that another reading of this phrase is, 'A human being is a human being through (the otherness of) other human beings' (Van der Merwe, 1996 in Berghs, 2017). Likewise, Bridget Bradley's (2021) framing of biosociality, as a concept that brings about shared relations built through shared biomedical conditions accounts for how having a condition that often means social isolation, because of stigma can build community.

Humanity is shaped and moulded by our experiences, both positive and negative, which have become embedded in our engagement with the world. This applies for both the observer and the observed, in this case me and whichever stranger that I encounter such as Arthur and the security guard from Chapter two. The same can be said about both Zikhona and Melikhaya from this chapter. In the same breath, Tatomkhulu and my proximity to him making me see his disability and altering my view of humanness, as my childhood self did not see another disabled person, Arthur, as fully human. Nomuzi from the previous chapter's ideas of dating a disabled person being about altering yourself (accommodating them) speaks to a power dynamic

between the observer and observed, that is, that the able-bodied person has more power over the disabled person that begins at being able to choose whether to wear the label disabled or not.

Through our conversations, I later learned that both, Zikhona and Melikhaya are much older than I am. Old enough to be my parents, in fact. But the interaction and subsequent interactions were void of the cultural expectations of performative politeness and gratitude expected from someone significantly younger, unlike the security guard in chapter two. The feeling of acceptance that I felt in that moment allows me to relate it to Nomuzi from chapter three, who was comfortable enough to move a certain way and tell me about her impairment. The previously mentioned concept of prioritisation can be used, where you highlight one identity over another to categorise this moment, as well, as the kinship seen in each other due to the commonality of being disabled taking precedent over other identities.

Berghs (2017) articulates that *ubuntu*, which is humanness, is ever evolving and changing over time and is profoundly shaped by our different experiences and diversity in humanity, whether positive or negative. This drives home a possible reason for the ethical sociality that was upheld by the disabled strangers I met and felt a kinship with. We shared a social experience, and it was unspoken. In the same breath, though, it is important to note and amplify the fact that even though *ubuntu* offers an understanding of the abstract, unspoken nuances and cultural cues that are held between Black people. *Ubuntu* has, in the same way, the ability to exclude and other, because the premise of *ubuntu* rests on ideas of normalcy and learned behaviours. Thus, when a person from a certain context identifies another person that they see as void of the attributes that they have given their *ubuntu* to, exclusion and further othering takes place. This is evident in my interactions with the Xhosa security guard from chapter two and his failure to recognise that I was human and an equal - just like him. In subtle and non-overt ways, he did not recognise my disability as an aspect of me that deserved or was entitled to *ubuntu*. Nor did most people in the community I grew up in as a child extend *ubuntu* to Arthur.

## **Disgust and making humans**

Livingston (2006) has framed disability in the context of south-eastern Botswana where many Batswana have become disabled from working in the South African mines. As Livingston (2006) acknowledges, her research of disability in Botswana is only a fragment, as Africa is much too large and disability not a definitive concept (Livingston, 2006). Livingston's (2008) subsequent article frames the human experience around various social relations and affects. I wish to home in on one of them: disgust. Disgust as a visceral emotion that often is experienced in relation to other people (Livingston, 2008). This phenomenon is akin to the "look" that I, a disabled person who uses assistive devices, have been subjected to and perpetually attempt to avoid when meeting people. How I attempt to avoid this, as discussed in the previous chapter, is by disclosing beforehand in instances where I meet someone online. Firstly, disclosing is a profoundly personal part of being physically disabled, yet it makes one's life public and open to public opinion. Secondly, with the logic that disabled people's existence is always related to the existence of others, we are inevitably at the mercy of whatever emotion it is that people experience when they see and look at us. Thirdly, the personal emotion such as disgust and any similar emotion being expressed after looking - or looking away (Cooper, 2020, 52) for that matter - has an unspoken effect on the disabled person that they carry into subsequent interactions. Garland Thompson (2009) shares a similar sentiment by saying that staring is a sometimes-uncontrollable physical urge that establishes a social relationship between the starrer and staree. In this way, an interaction that refutes the negative affective consequence of being stared at and induces shame is surprising.

The story of Tatomkhulu and the story of Arthur are opposites in that both of their disabilities are experienced and thought of differently by the other members of the community to which they belong. Tatomkhulu is regarded as a full person and afforded complexity, but Arthur is conflated with his disability. Their respective roles and identities in the community directly tie into how their respective disabilities are viewed and the levels of stigma that they receive. Arthur, having a mental disability that is widely known of in the community, is the scapegoat for the crimes against women and girls that take place in the township and is not afforded compassion, respect or humanity. Tatomkhulu, on the other hand, is a member of a family and constantly in the public eye as a pastor. Arthur does not have the role of being a father, grandfather or husband that Tatomkhulu has and is respectable for.

Returning to Reynolds Whyte & Ingstad's (2007) argument about the importance of circumstance, that is, the time, place and the conditions that a moment is produced by (complete the sentence). The conditions under which Arthur and Tatomkhulu existed shaped my internal views of disability, even when so many years have passed. The time has changed and so has what I look like and what disability looks like. Context, Reynolds Whyte & Ingstad (2007, 1) state, is a fundamental principle of anthropology, as it allows for another important aspect to take place: comparison. They refer to cultural circumstance as the idea that the accumulations of our cultural contexts and experience is directly tied to personhood which according to Lubarsky (1994) is the accumulation of factors that render an individual a full person. Personhood includes factors such as age and status which is an interesting and fundamental concept to think through my encounter with Tatomkhulu.

What I did not realise was that up until that moment Tatomkhulu was a *full person* (Lubarsky, 1994). I had been socialised into thinking of and observing disability and what it makes or, in this case, un-makes, a person. It suggests that disability scrapes away factors that give a person the full extent of their personhood. Which is another reason for the stigma Arthur was subjected to. This is particularly evident because it is in stark contrast with Tatomkhulu being a pastor. Moreover, the shock and surprise that I expressed in the ethnographic vignette when seeing Tatomkhulu remove his prosthetic leg catapulted me into something I participated in involuntarily: staring. As I have mentioned earlier on in this thesis, the act of staring when seeing something unusual, that is, a disabled person minding their own business evokes a variety of emotions, which ultimately has the potential to grow into feelings of disgust, pity, curiosity and many more (Livingston, 2008). As reflected on in the previous chapter, as well as this one, positive emotions such as care can also be a reason why one would stare. The multi-layeredness of how I related to him affords the moment much more complexity than only the negative.

Being looked at, something that I experience a lot because of my assistive devices, varies when you are at the receiving end. For example, I do not always know why I am being looked at, even though I often am. On the other hand, when I am looking at someone with a disability (not at the receiving end) it is because I want them to feel a level of solidarity from me. I know, though, that when you are at the receiving end of "the look" you do not know which one is

threatening and which one is not, thus being looked at is frightening, uncomfortable or even threatening. I notice people looking to investigate where the “defect” or “problem” might be. The look I receive most is one of pity, however, in different contexts.

## **Conclusion**

*Ubuntu* is described as an African humanity by some scholars, which does not mean it is an ethos of all Black people. On the contrary, *ubuntu* can be exclusionary and unsafe, which is shown to us in the way that Arthur is treated in the community compared to Tatomkhulu. Merely belonging to a community does not mean that the said community does not enforce beliefs held by individuals within it and that communities are not subject to oppressive systems like gender-based violence and ableism. Zikhona and Melikhaya, two people who were older than me, did not require me to display any performative politeness, as cultural social cues would dictate. Our shared identity of being disabled instead took precedence and brought solidarity. Being looked at or stared at, an occurrence that has been shown to shape social relations between the starrer and staree, that is, that the able-bodied and disabled has endless affective consequences for both.

## **Conclusion**

Focusing on my history and lived experience and doing memory work through autoethnography has shown how the affective quality of my interactions with able-bodied people, as well as other disabled people created my disability experience. Autoethnography was a viable way to document, research and write about my life in conversation with disability theory as disability is personal and political and moreso, a largely underrepresented subject in academia and literature. Being an able-bodied child and then becoming a disabled adult who uses assistive devices while sitting down, and while standing up illustrates the concomitant affective differences, nuances and complexities which are further amplified by naming my assistive devices.

Physically disabled people often rely on assistive devices to navigate the world. Assistive devices do not only simplify movement for the disabled, but they can also be thought of as a shaper of the social experience between the disabled, the able-bodied and the world. As disabled people navigate the world, they often make decisions such as naming their assistive devices to re-enforce and solidify the importance of their devices, among other reasons. As a Xhosa person, there are ritualistic processes that I have undergone and participated in where I received the various names that I have. Similarly, the naming of assistive devices bears similarity to rites and ritualistic processes that award us our names. Naming is also associated with permanence. Thus, naming my walking stick Mantoa is akin to that importance and shapes my view of my own permanent disability to harbour value that is similar to rites and rituals. In naming Mantoa, I first introduced her to myself and, in turn, naming my devices allows me to introduce myself and navigate those introductions.

Naming can also be a sign of the manifestation of the internalisation of ableism such as when I named a wheelchair after a disabled man, Arthur, from my childhood that I feared. This is a sign of the affective nature of disability and the nuanced complexity thereof. The affective possibilities and consequences of being on the receiving end of a look or stare from able-bodied people is another inevitable consequence of being physically disabled. In other words, our histories of disability live inside of us and manifest under particular conditions. Being looked at or stared at as a disabled person who is simply minding their business can have varying meanings for the starrer and the staree. Like, when I saw Tatomkhulu's prosthetic leg for the

first time as an able-bodied child, the stare that I exercised was governed by what I had been socialised into believing about who gets full personhood. Tatomkhulu, a respected elder, being disabled like Arthur, whose humanity was not recognised, made me stare in disbelief.

Disabled people's interactions with able-bodied people show that navigating bureaucracy can be challenging. The bureaucratic nature of navigating institutions where people who have been authorised to control access can be gatekeepers and shape your experience of the world and yourself. Able-bodied people in positions of power in institutions, like security guards at university residences can make receiving access a deeply difficult and bureaucratic process, causing insecurity for disabled people when they are meant to uphold security. In this way, when unspoken cultural cues exist, which is one of the ways *Ubuntu* is described, we are shown that *Ubuntu* can be destructive and not a metaphoric fire that all Black people sit around. Thus, when *ubuntu* is a prerequisite that is considered important in upholding relations (like having to be a certain way to receive the desired outcome of receiving the access that you are entitled to) we are shown how the second chapter's conceptualisation of bureaucracy as a metaphor for how institutions employ people like the security guard who have the power to control access is in conversation with the final chapter's conceptualisation of *Ubuntu*, an ethos that allows us to recognise each other's humanity, but our social access depends on whether we are perceived as human or not. Stigma being the theme that continually emerged throughout this thesis, and which produces ableism and internalised ableism, is ever-present.

In chapter three, questions of desirability and dating were discussed. It is not uncommon for disabled people to move in different and complex ways to perform ordinary tasks. The aesthetic of their assistive devices also, then, becomes of heightened importance to the disabled person themselves, however this is not exclusive to dating. Continuing with the complexities of disability and dating, the idea that care could be synonymous with ableism was brought forward, as care can be performative, as the idea that disabled people automatically need care in dating can be dehumanising. I located and interrogated my own internalised ableism, as I named a wheelchair that was meant to assist and liberate me after Arthur, a scary mentally disabled man from my childhood. This, and the idea of bodies moving differently, is a manifestation of the theory of complex embodiment which provides tools to understand and unpack the subtle meanings behind interactions between the disabled or between the disabled

and the able-bodied. When this is observed by able-bodied people or even by other disabled people whose disabilities are different, that observation stands as a social relationship.

Chapter four looks at community and *the look* as a concept that I explore through my encounter with Tatomkhulu as a child and seeing his disability. Comparing why I looked and stared back then to how I feel about (being on the receiving end of) *the look* as a disabled adult nudges me into unpacking how *the look*'s meaning has changed, for me, through different times and contexts. Furthermore, *the look* evokes different and particular emotions and memories for both the observer and the observed in a way that is similar to *ubuntu*. *Ubuntu* is dissected and critiqued as a concept that is synonymous to personhood and humanity. To whom full personhood is given depends on one's socialisation, contexts and perhaps even one's history. The look and *ubuntu* can be equally well-intended or, completely void of intention, but their effects can be seen as being in conversation with each other. Many, if not all, of the conceptualisations and theorisations that emerged during this research process can also be viewed under such a lens.

## References

- Addlakha, R. & Das, V., 2001. Disability and Domestic Citizenship: Voice, Gender, and the Making of the Subject. *Public Culture*, 13(3), pp. 511-53.
- Addlakha, R., Price, J. & Heidsri, S., 2017. Disability and Sexuality: claiming sexual and reproductive rights. *Reproductive Health Matters*, 25(50), pp. 4-9.
- Bailey, J. & Steeves, V., 2015. *eGirls, eCitizens: Putting technology, theory and policy into dialogue with girls' and young women's voices*. Ottawa: University of Ottawa Press.
- Berghs, M., 2017. Practices and discourses of ubuntu: Implications for an African model of disability?. *African Journal of Disability*, 6(292), pp. 1-8.
- Boon, S., 2013. Vulnerability, Longing, and Stigma in Hélène Cixous's "The Day I Wasn't There". *SubStance*, 3(132), pp. 85-104.
- Brown, R. L., 2016. Understanding the influence of stigma and discrimination for the functional limitation severity e psychological distress relationship: A stress and coping perspective. *Social Science Research*, 62, pp. 150-160.
- Campbell, F. K., 2009. *Contours of Ableism: The Production of Disability and Abledness*. London: Palgrave MacMillan.
- Campbell, F. K., 2020. The Violence of Technicism: Ableism as Humiliation and Degrading Treatment. In N. Brown & J. Leigh (eds). *Ableism in Academia: Theorising experiences of disabilities and chronic illnesses in higher education* (pp. 202-224). London: UCL Press.
- Clark, C. D., 2012. Asthma Episodes: Stigma, Children, and Hollywood Films. *In Medical Anthropology Quarterly*, 26(1), pp. 92-115.
- Coertze, R. D., 2007. Racism and ethnicity': Reflections on the debatable permanence of terminology. *Anthropology Southern Africa*, 30(1), pp. 11-19.
- Cooper, H., 2020. *Critical disability studies and the disabled child: Unsettling distinctions*. London & New York: Routledge.
- Couser, G. T., 2015. Illness. In: R. Adams, B. Reiss & D. Serlin, eds. *Keywords for Disability Studies* (pp. 105-107). New York: New York University Press.
- Crenshaw, K., 1989. Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Policies. *The University of Chicago Legal Forum*, 1989(1), pp. 139-167.
- Davis, L. J., 1997. Nude Venuses, Medusa's Body, and Phantom Limbs: Disability and visibility. In D. T. Mitchell & S. L. Snyder (eds) *The body and physical difference: Discourses of disability* (pp. 51-70). Ann Arbor: The University of Michigan Press.

- Ellis, C., 2013. Preface: Carrying the torch for autoethnography. In: S. Holman Jones, T. E. Adams & C. Ellis, (eds). *Handbook of autoethnography* (pp. 9 - 12). London & New York: Routledge.
- Erevelles, N. & Minear, A., 2010. Unspeakable offenses: Untangling race and disability in discourses of intersectionality. *Journal of Literary & Cultural Disability Studies*, 4(2), pp. 127-146.
- Fairbairn, J., 2015. *Ecologies of Change: Violence Against Women Prevention, Feminist Public Sociology, and Social Media*. Carleton: Carleton University.
- Frederick, A., 2017. Risky mothers and the normalcy project: Women with disabilities negotiate scientific motherhood. *Gender & Society*, 31(1), pp. 74-95.
- Garland-Thompson, R., 2009. *Staring: How We Look*. London: Oxford University Press.
- Garland-Thomson, R., 2017. *Extraordinary bodies: Figuring physical disability in American culture and literature*. New York: Columbia University Press.
- Ginsburg, F. & Rapp, R., 2013. Disability worlds. *Annual Review of Anthropology*, 42(1), pp. 53-68.
- Goethals, B., Naulaerts S., Meysman, P., Bittremieux, W., Nghia Vu, T., Vanden Berghe, W., Laukens, K. 2015. A primer to frequent itemset mining for bioinformatics. *Brief Bioinform*, 16(2), pp. 216-231.
- Goffman, E., 1963. *Stigma: Notes on the Management of Spoiled Identity*. New York: Simon & Schuster.
- Golos, D. B., Moses, A. M. & Wolbers, K. A., 2012. Culture or disability? Examining deaf characters in children's book illustrations. *Early Childhood Education Journal*, 40(4), pp. 239-249.
- Goodley, D., Liddiard, K. & Runswick-Cole, K., 2018. Feeling disability: Theories of affect and critical disability studies. *Disability & society*, 33(2), pp. 197-217.
- Harding, S., 1992. Rethinking Standpoint Epistemology: What Is Strong Objectivity?. *The Centennial Review*, 36(6), p. 34.
- Harris, J. E., 2019. The aesthetics of disability. *Columbia Law Review*, 119(4), pp. 895-972.
- Holness, W., 2013. Informed consent for sterilisation of women and girls with disabilities in the light of the Convention on the Rights of Persons with Disabilities in Agenda: Empowering Women for Gender Equity. *Agenda*, 27(4), pp. 35-54.
- Hough, C., 2016. *Oxford Handbooks in Linguistics*. Oxford University Press: London.
- Hunt, X. et al., 2018. Dating persons with physical disabilities: The perceptions of South Africans without disabilities. *Culture, health & sexuality*, 20(2), pp. 141-155.

- Jacobson, S., 2010. *Overcoming the Stigma Associated with Assistive Devices*. Accessed at <https://core.ac.uk/download/pdf/211815528.pdf>
- King, S., 1990. Naming and Power in Zora Neale Hurston's *Their Eyes were Watching God* in. *Women Writers Issue* , 24(4), pp. 683-696.
- Kroger , T., 2009. Black American Literature Forum Care research and disability studies: Nothing in common?. *Critical Social Policy*, 29(3), pp. 398-420.
- Livingston, J., 2008. Disgust, bodily aesthetics and the ethic of being human in Botswana. *Africa*, 78(2), pp. 288-307.
- Marks, D., 1997. Models of disability. *Disability and rehabilitation*, 19(3), pp. 85-91.
- McClure, T., 2019. Reducing service sabotage and improving employee commitment to service quality. *Journal of Services Marketing*, 33(5), pp. 615-635.
- Mitchell, D. T. & Snyder, S. L., 2014. *Narrative prosthesis: Disability and the dependencies of discourse*. Michigan: University of Michigan Press.
- Mittleman, A., 1994. Lubarsky, "Tolerance and Transformation". *The Jewish quarterly review*, 84(4), pp. 521-522.
- Mji, G. et al., 2011. An African Way of Networking Around Disability. *Disability and Society*, 26(3), pp. 1-17.
- Mohamed, K. & Shefer, T., 2015. Gendering disability and disabling gender. *Agenda*, 29(2), pp. 2-13.
- Nayaran, K., 1993. How native is a " native" anthropologist?. *American anthropologist*, 29(2), pp. 95-3.
- Oliver, M., 1997. The disability movement is a new social movement!. *Community Development Journal*, 32(3), pp. 244-251.
- Parette, P. & Scharer, M., 2004. Assistive Technology Use and Stigma in Education and Training in Developmental Disabilities. *Education and Training in Developmental Disabilities*, 39(3), pp. 217-226.
- Penn, C., 1993. Signs of the times: Deaf language and culture in South Africa. *South African Journal of Communication Disorders*, 40(1), pp. 11-23.
- Pescosilido, B. A., 2013. The Public Stigma of Mental Illness: What Do We Think; What Do We Know; What Can We Prove?. *In Journal of Health and Social Behavior*; 54(1), pp. 1-21.
- Ralph, M., 2012. Notes on the relationship between slave insurance, life insurance and disability. *Disability Studies Quarterly*, 32(3), pp. 1-17.

- Reynolds Whyte, S. & Ingstad, B. 2007. Introduction: disability connections. In B. Ingstad. & Reynolds Whyte, S. (eds) *Disability in local and global worlds* (1 – 26). Berkeley, Los Angeles & London: University of California Press.
- Richards, R., 2008. Writing the othered self: Autoethnography and the problem of objectification in writing about illness and disability. *Qualitative health research*, 18(12), pp. 1717-1728.
- Ripat, J. & Woodgate, R., 2010. The Intersection of Disability, Culture and Assistive Technology. *Disability and Rehabilitation: Assistive Technology*, 6(2), pp. 87-96.
- Shakespeare, T., 2000. Disabled sexuality: Toward rights and recognition. *Sexuality and disability*, 18(3), pp. 159-166.
- Siebers, T., 2004. Disability as Masquerade. *Literature and Medicine*, 23(1), pp. 1-22.
- Siebers, T., 2013. Disability and the theory of complex embodiment—for identity politics in a new register. In L. Davis (ed.) *The disability studies reader, 4<sup>th</sup> Edition* (pp. 278-297). New York & London: Routledge.
- Slobogin, C., 2000. Mental Illness and the Death Penalty in Mental and Physical Disability. *Law Reporter*, 24(4), pp. 667-677.
- South African History Online, 2020. *South African History Online*.  
 [Online] Available at: <https://www.sahistory.org.za/>  
 [Accessed 3 December 2021].
- Statistics South Africa, 2011. *Census 2011*. Pretoria: Statistics South Africa.
- Suchet, M., 2011. Crossing over. *Psychoanalytic Dialogues*, 21(2), pp. 172-191.
- Titchkosky, T., 2020. Disability imaginaries in the news. In K. Ellis, G. Goggin & B. Haller (eds) *The Routledge companion to disability and media* (pp. 13-22). New York & London: Routledge.
- Van der Heijden, I., Harries, J. & Abrahams, N., 2019. In pursuit of Intimacy: Disability Stigma, Womanhood and Intimate Partnerships in South Africa. *Culture, Health & Sexuality*, 21(3), pp. 338-351.
- World Health Organization (WHO). 1976. *Health aspects of human rights : with special reference to developments in biology and medicine*. Geneva: Switzerland.
- Wynberg, N., 1983. Social equity and the physically disabled. *Social Work*, 28(5), pp. 365-369.
- Yang, L. H., Purdie-Vaughns, V., Kotabe, H., Link, B. G., Saw, A., Wong, G., & Phelan, J. C. 2013. Culture, threat, and mental illness stigma: identifying culture-specific threat among Chinese-American groups. *Social Science & Medicine*, 88, pp. 56-67.

Yang, L. H., Kleinman, A., Link, B. G. & Phelan, C., 2007. Culture and stigma: Adding moral experience to stigma theory. *Social Science and Medicine*, 64(7), pp.1524-1535.