

**EXPLORING THE PSYCHOLOGICAL AND EMOTIONAL
IMPACT OF ABLEISM IN EDUCATION AND
MOTHERHOOD**

A TALE OF TWO PARTS

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I hereby declare that, except where explicit attribution is made, the work presented in this thesis is entirely my own.

Ableism is everywhere. Its practices often operate under the guise of rationality, but they are toxic and pervasive. This programme of research addresses the psychological and emotional consequences of ableism in society, focusing particularly on two fundamental areas of social life: education and motherhood. The thesis will thus be divided into two separate but interrelated projects. Drawing on a range of theoretical orientations - Studies in Ableism (SiA); critical social psychoanalysis; and postconventionalist theories – I consider how the twines of ableism permeate into the concepts of being a ‘good’ student and a ‘good’ mother.

Project One interrogates neoliberal ableism within the lives of disabled university students. It is conducted using a research design that reflexively reconsiders normative assumptions concerning the naturalisation of speech and the written word. The findings indicate that disabled students are positioned in the ableist imaginary as unruly and demanding, in stark contrast to the vision of the ‘ideal’ student who is autonomous, self-regulatory, and compliant. This vision can be reabsorbed into the minds of disabled students, leading them to disavow and reject their disability, or endeavour to ‘pass’ as non-disabled. Both these reactions can cause a significant amount of psychological and emotional distress.

Project Two seeks to unmask the values that nourish the ideology of motherhood (ableism’s production) and analyse how we as a society reinforce these values (ableism’s performance). It frames the ways in which disabled mothers potentially resist and challenge these normative notions. I use my position as an insider- researcher to strengthen my critical positionality, using my particular vantage point to unravel the complexity of threads that make up the entrenched social perceptions of what it means to be a mother, revealing the rotten core of neoliberal capitalist values at its root. Through this, we can begin to challenge and refuse such limiting concepts. Using postconventionalist theories I position disability as a productive force that refutes neoliberal ableist normativity, and enables new knowledges to be created that incorporate embodied vulnerability and the necessity of living interdependently with others.

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DEDICATION

This thesis is dedicated to my daughters, Jasmine Rose Nahal Daniels and Mia Jeet Nahal Daniels. You are my sunshine and my light; my warmth and my glow. You are my world, and I love you dearly.

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PREFACE

This thesis is comprised of two separate but interrelated research studies. I will invite the reader to accompany me on a journey that explores the psychological and emotional impact of ableism as it ravages the societies we live in, permeating the ethos of conventional thinking. The programme of research that follows in these studies will attempt to expose the production of ableism in two vital areas of concern: education and motherhood. I will show through these studies the dysconscious (King, 1991) processes through which ableism combines forces with neoliberalism, morphing to create brutally narrow and limiting restrictions on ways of being human.

Dysconscious processes are seen in the tacit acceptance of the status quo. King (1991) initially coined this term to refer to the hegemonic compliance with the dominance of White norms and prerogatives, and I infer that the ways in which ableism is carried out, at times almost imperceptibly, operates along similar lines. Ableism, briefly, can be defined as discrimination in favour of non-disabled people. However defining it as such belies the impact that it has on wider relations in society, as the reader will understand through exploring this research journey with me. Dysconscious ableist relations play out most significantly in the unquestioned acceptance of ability privilege – the implicit approval that that *of course* impairment is inherently and permanently negative. Ableism occurs often not in the overt practices of active discrimination, but in the unspoken, inadvertent conventions that reify the dominance and the preferential treatment of non-disabled people. This distorted way of thinking about disabled people congeals with the rotten core of neoliberal selfhood – the narcissistic, inward-looking, fragile self that is always in suspicious competition not only with others but themselves; anxiously seeking to progress towards a never-ending goal.

Neoliberalism as defined in this thesis is a political and philosophical model that that has become dominant in the West, influential globally yet pleases few beyond an economic elite. It is a model that aims to transfer control of economic factors from public sectors to private sectors, and operates through deregulation, reduced government spending and free-market capitalism (Harvey, 2005). Economic inequality is seen by this system not as unfortunate, but instead as a prerequisite for creating the necessary conditions in which self-entrepreneurship can take place. It is a system that legitimises a certain view of society, with the structural inequities being justified under the illusion that those particular individuals are in oppressive situations largely through lack of planning, lack of intelligence and through their own choosing.

It is the internalised scripts that the unquestioned belief in these lies are providing - the ones that say, 'the only limitations are the ones I set for myself', ignoring the realities of, for example, poverty, rampant social inequality or providing for dependent children (Davies, 2016) - that concern me in this programme of research. The internalisation of scripts such as these are essential for neoliberalism to take seed and reproduce within the minds of individuals. I will argue that the processes of internalised ableism – which I shall be describing at length throughout this thesis – are a key factor in the reproduction of neoliberal ableist subjectivities. The research questions that I am trying to address in this thesis concern the interrelationship of society and the psyche, and the psycho-emotional consequences of this interaction in the context of education and motherhood, touching on the ableism within the research encounter. My concern is how this socially orientated self-perception is incorporated within the psyche and thus this phenomenon is able to perpetuate. It is the dysconscious seepage of neoliberal ableist values into vital areas of society that this programme of research seeks to uncover. I will argue that through this seepage prevails a frantic and exhausting compulsion of disabled people to emulate the norm, be that the ideal student; the ideal researcher; or the ideal mother.

The explicit research questions for Project One are as follows:

- How is the neoliberal ableist agenda inculcated into university institutions?
- How does this impact upon the psycho-emotional well-being of disabled students?
- What alternatives could be conceived of for the future of education that goes beyond the neoliberal agenda?

These research questions will allow the practices and procedures undergirding university institutions to be thoroughly inspected, and for the ableism within them to be accentuated and purged.

The research questions for Project Two are:

- What is it specifically that is valued in motherhood, and in what ways are these values ableist?
- How do we as a society uphold and reinforce these values?
- How can the study of ableism, in conjunction with a social psychoanalytical and post conventionalist approach, be used first to expose then to challenge and break down these stifling structures in order to forge a path for more creative mothering practices?

Project Two will be explored in relation to pregnancy, childbirth and early motherhood. These questions will interrogate the ableist practices that pass by almost unnoticed, but have the potential to damage the lives of disabled women. It is my hope that through these two projects we can begin to re-evaluate the borders of our humanity, consciously and consistently reflecting upon the values we want to instil upon the minds and hearts of the children of tomorrow.

The thesis is divided into three sections. Section 1 will ground the studies in theoretical orientations and set the stage for the programme of research as a whole. Section 2 will introduce Project One; exploring neoliberal ableism in the lives of disabled university students. This study will emphasise the psychological and emotional impact of neoliberal ableist policies and practices on disabled students, and suggests that neoliberalism as a political ideology has had remarkable, overwhelmingly negative effects on tertiary education and upon disabled students in particular. Treating the student as consumer has, arguably, allowed grudging improvements to be made in terms of treating the student fairly, by providing accommodations – ‘reasonable adjustments’ for example. This does nothing, however, to disrupt the ‘able-as-desirable’ rubric at the heart of ableist egotistical superiority.

Section 3 will introduce Project Two; exploring ableism within mothering ideology. This study will seek to expose the concepts held deep within the idealisation of the mother figure, and suggests that these concepts can be damaging to all women. Social psychoanalytic theory is both implicated in the hegemonic acceptance of the ideology of motherhood, and can be used to shed light on the production of ableism in this realm. Both studies will use postconventional theories to suggest the need to think beyond the confines of neoliberal ableist ‘inclusion’ to the ways in which disability in and of itself signals productive ways forward – with the focus on interconnection, cooperation, togetherness, and community.

In Section 1, Chapter One will outline my ontological, epistemological and theoretical orientations. This is important as it will flavour the directions of the programme of research. Chapter Two will build on the work of Fiona Kumari Campbell (2001- present) especially her re-articulation of the ‘problem’ of disability to the ‘problem’ of ableism. It will elaborate upon my use of ableism, both as a concept and as an analytical tool. It will describe the ways in which ableism will be revisited throughout this thesis to explore neoliberalism in the lives of university students; ableist methodologies; and conventional depictions of the ideal mother.

In Section 2, Chapter Three will introduce the methodology that will be applied to Project One, justifying my application of the interpretive paradigm and clarifying my use of online methods. My method of analysis will be introduced, with a detailed explanation of my analytical process. Chapter Four will ruminate upon speech; and the conventional acceptance of speech in research contexts as a naturalised, neutralised and universalised method of communication. It will also interrogate my use of online methods and the primacy of the written word, and begin to ponder alternative ways of relating. Chapters Five and Six will be comprised of the data analysis for Project One, exploring the ways in which the concepts drawn from this study can be applied to the creation of a more equitable society. Chapter Five will explore the themes of belonging; lack of support; and internalised oppression narrated by my participants for Project One. There is an inherent danger in exploring themes such as these, as it focuses on the ‘lack’ and on where my participants have struggled to justify their existence. Applying a Studies in Ableism lens to these blatant acts of microaggression, however, we can understand them as dysconscious practices acting to uphold the dominance of ablebodiedness. In Chapter Six, I frame disability as a productive force wherein my participants sought to defy the strangulation of neoliberal ableist ideals and propose new ways of being human.

Section 3 will concern itself with the exploration of ableism in the ideology of motherhood (Project Two). I will take you on my journey into motherhood, through the feelings of trepidation that constantly interrupted my feelings around becoming a mother. I felt bombarded by the insinuation that, as a disabled person, I shouldn’t assume that I have the right or the capacity to become one. Using the spirit of Studies in Ableism, however, I turned my experiences of distress into genuine learning possibilities. Why, for example, are pushchairs not designed with the disabled body in mind? What are the values attached to being a good mother? How do we as a society reinforce these ideals? How are they manifested? I found in this personal reflection a site wherein I could enhance my study of the psychological and emotional impacts of ableism in a completely different realm. Through my engagement with radical and critical literature, I began to see the insidious relics of ableism propping up the ideology of motherhood. I finally began to challenge and speak back to these stifling systems, and to see how disabled people especially can refute and refuse these ways of living.

Chapter Seven will introduce the rationale for this study; why I felt it was a necessary area of concern; and my role as an insider-researcher on this topic. This chapter will outline the methodology, and indicate the theoretical frameworks that will be used to ‘out’ the ‘able’ (Campbell, 2008). Chapter Eight will explore the medicalisation of childbirth and child-

rearing, focusing particularly on the ableist biopolitics of the pregnant body. Chapter Nine will use a critical social psychoanalytical lens to expose the production of ableism, and to shed light on how these practices are maintained and the potential consequences for disabled mothers. Chapter Ten will begin to break the spell of compulsory able-bodiedness. It will show how, by their very embodiment, disabled mothers are 'lack of support of the lack' (Wilton, 2003). The unattainable standards of current mothering ideology are an issue for all mothers, not just disabled mothers. This is the dizzying reach of ableism; it delves in and holds the power to strangle each and every act we perform, but does it in a way that is so stealthy that it almost passes by unnoticed. The realisation of this - and the active promotion of alternative ways of being - is a central aim of this programme of study. Chapter Eleven is a discussion of the key insights of this programme of research, and will endeavour to show how these seemingly discrete microcosmic studies overlap and interconnect to reveal wider instances of ableism in western society. This chapter will suggest recommendations for a future in which the possibilities and potentialities of engaging with the teachings of disabled embodiment can be celebrated.

SECTION 1:
GROUNDING THE THESIS

CHAPTER ONE: ONTOLOGICAL, EPISTEMOLOGICAL AND THEORETICAL ORIENTATIONS (AND WHY THEY MATTER)

1.1 Overview

It is a contention of this thesis that neoliberalism and ableism coalesce to form a powerful, pervasive and seemingly impenetrable force that governs much of Western society. This force both hungers for and enforces homogeneity, and it depends on the desire for sameness amongst its subjects for its survival. It enforces this desire by rejecting those who are not-same, hounding them away but at the same time offering them glimpses of the mythical fantasy of the ‘good life’ purportedly enjoyed by those who conform (Berlant, 2010). It is the psycho-emotional effects of this force upon disabled people that I wish to focus on, particularly among disabled students and disabled mothers. The reasons for this will become clear as I take you with me on a journey to interrogate ableist values and ideals.

I feel that the way that neoliberalism is encroaching on education is frightening. Perhaps I have rose-tinted glasses, but in my mind education at its most basic should be about developing and nurturing our minds and fostering new skills. It should be about learning ways in which we can live together, not in competition with each other. Project One is pursued with these thoughts in mind. What are the values undergirding contemporary education, and to what extent are tertiary students bewitched by these? It is a contention of Project One that neoliberalism co-opts ableism within educational goals, and they feed off each other to create ever more exclusionary borders of humanity.

Universities are an ideal site of enquiry into the extent to which education has been infiltrated by neoliberal ableist ideals. Project One will explore what this increasing trend means for the spirit of education, and will think through the possible psychological and emotional repercussions the sentiment of ‘student as consumer’ has, particularly for disabled students. I feel that as university students, we will be more assessed on, for example, our ability to attend extra-curricular activities; tick the boxes; produce endless papers; attend and present at numerous national and international conferences; and so on. In this valuation, there is little thought given to a student’s care-giving responsibilities; pain experienced when travelling; or lack of accommodations given at conferences. The idea of a level playing field gets farther and farther away.

Project One gave birth to a screaming need to conduct research differently. This, as we will see in Chapter Four, gives rise to what is in effect a separate study, based around the search for alternative and appropriate methods for research production.

In Project Two, I aim to uncover what, exactly, are the values incorporated within ideal motherhood? How are disabled mothers positioned in the social imaginary as being incapable? And, to invoke C. Wright Mills (1959), how do these personal troubles relate to social issues? In an ideology where we are encouraged to think of our own requirements first, what value is there in mothers dismissing their own needs? This is a necessary avenue of exploration if we are to turn our private moments of distress and frustration into moments of socio-political importance, possibility and potential.

All of these projects had the same theoretical grounding, which will be outlined in this chapter. Project One exposes the normalisation procedure that creates the ‘able-disabled’, and Project Two works along the same theoretical grounding to uncover the processes of internalised ableism, where, for example, I pushed myself to mirror the ‘ideal’. What these seemingly discrete studies have in common is they all outline the ‘ideal’ to which disabled embodiment is held up and rejected; they all attempt to provide the possible reasoning for these ideals; they all relate the findings to neoliberal ableist ideology; and they all suggest ways in which disabled people, by their very embodiment, can dispute and challenge these constrictive ideals.

In these studies I found that my unconventional embodiment jostled and butted against normative ways of doing things. At the start of the journey, as you will see, I am tentative and apologetic, needing to excuse the way that my body prevents me from performing activities or thinking in a way that I deem to be expected of me. Through my engagement with radical and critical literature I learn to critically analyse the myriad of ways in which ableism infiltrates and infects our perceptions of who we are and who we can be. By exposing these ideals as part and parcel of ideologies that have their own very specific aims and objectives, we can ask ourselves whether or not we want to be embraced and engulfed by them; or whether we can be free from the chains that bind us to neoliberal ableist ideals.

This story will begin with an outline of my ontological position. This, as we shall see, informs the theoretical journey that we will travel on, taking twists and turns, retracting and retracing our steps in a sometimes maddening array of contradictions. I warn you now; there will be no apology for this. Life is full of contradictions, of ‘messiness’ and stops and starts. Nor will my theoretical orientations merge to form a holistic, integrated synthesis. Rather, I am hoping that

they will retain their analytical power by *not* attempting to smooth out the creases, obscuring the tensions and thereby silencing them. What I am seeking to do is listen to the voices that these theories are offering, nurturing and validating each and every one. I will ask the reader, therefore, to accompany me on a theoretical and philosophical venture through a Studies in Ableism approach, touching on social constructionist thought. We will then dip our toes into the pool of phenomenology, pondering how western society, although widely purported to be ‘free’, has been kept on a leash which restrains the comportment of us all. We will then proceed to the turmoil of critical social psychoanalysis, considering especially the notions of disavowal and emotional labour; finally, opening out to the possibilities and potentialities of Crip theory and postconventionalist theories (Shildrick, 2009; 2012). I hope you will enjoy the journey.

1.2 My Ontological and Epistemological Values

In any piece of robust, thorough research, ample justification will need to be given as to the particular stance of an individual researcher, which is largely supported by their ontological and epistemological assumptions. The latter assist the researcher in framing their research questions. My thoughts on the preferential treatment of methodologies and philosophical decisions will, I hope, become clear as I invite the reader to share the tensions and discords encountered in the research journey with me. Part of what I am trying to achieve in this exploration is to provide an explicit reflection on my view of the nature of reality (ontology) and how we can come to know about this (epistemology) in an attempt to offer ‘procedural transparency’ (Yanow& Schwartz-Shea, 2006:xiv).

The research questions that I am trying to address concern the interrelationship between society and the psyche, and in particular the psycho-emotional consequences of this interaction in the context of education and motherhood. Thus, I am seeking to assemble a multitude of voices to guide me in accumulating a subjective sense of how and why this relationship occurs, with what effect, and how this socially orientated self-perception is incorporated within the psyche, allowing this phenomenon to reproduce. These types of questions require a very personal, in-depth analysis of the meaning-making of people *in relation* to the particular environments they live in and how they see themselves as operating with/in their worlds. This has profound implications for my choice of paradigm, the type of methods I will use, and the techniques I will be employing in my study. It also has implications for the theoretical approaches that I will be applying as conceptual frameworks for my analysis.

First, the reader can expect to find a brief outline of my positionality, which is informed by my ontology and epistemology. I feel this is key to the reader developing a deeper understanding of my particular life world and my view of my position within this world. I will then go on to describe the theoretical orientations that will be informing my analysis, and relate why these approaches appeal to me and why they may be useful in my analysis of ableism.

1.3 Positionality

There are a number of different elements that blend to constitute my being-in-the-world, which I feel have all furnished me with a particular understanding of the world around me. As is common with every individual, there are elements of identity – gender, age, sexual preference, ethnic background and so on – that are more significant (by that I mean more important to how they characterise themselves, more challenging, more troubling) than others. For example, I am a mother, wife, daughter, aunt, cousin, friend, student and member of the graduate research centre (among other things). I am also of mixed ethnic heritage; my father is Caucasian and my mother is Indian. I grew up in a very white, monocultural village, and this had the effect of me always experiencing myself as an outsider. I am used to being positioned on the outside looking in, and yet, and yet... this positioning *still* has the power to trouble me deeply. As I am writing this, my membership of the graduate research centre (GRC) is of primary importance to me, as this social space allows me into a prestigious world wherein I have access to the necessary facilities to carry out research, engage in writing or other tasks that are important to my progression as a PhD candidate. However, the kitchen and print services are upstairs in this building, through two very heavy restricted-access doors, meaning that I cannot comfortably come and go with a mug of hot coffee and/or printed copies of the required journal or other resources as I see many other users of this facility doing. This is where my identity as a disabled student comes into play and demands my attention. My academic position affords me a privileged status, but certain spaces are effectively denied to me through their normative structuring. There is no provision (other than lifts) for students with differing mobility or energy needs. The experience of having a multitude of metaphorical doors open to you through being part of a team of researchers working toward change, and then the experience of exasperation at the insensitive way in which some institutions perceive ‘accessible’ zones, creates a somewhat fractured sense of self-worth. Although this tale suggests more of a minor inconvenience than a real point of access concern, it provides the reader with a glimpse into my world; a stark reminder that I am not quite and never will be ‘normal’ (whatever that means). My ‘rational and objective’ self tells me that I am being too sensitive, too ‘picky’ by

wanting to address these concerns, although a disability studies perspective may see these concerns as a form of ontological violence, as they do force my very sense of *belonging* in this university setting into question.

What I am trying to express here is that I believe we all have a multitude of selves that present themselves in different social situations, and that the way we respond to these situations involves a complex interaction of personal, historical, social and emotional factors that are unique to us. In this way I can be said to be a social constructionist, believing that we build our worlds through internal constructs that are assembled on the basis of encounters with external discourses, past experiences and our internal perceptions of those experiences. This may be an overly simplistic view of social constructionism, but it is the way in which it understands the relationship between individuals and the social that appeals to me, and that I feel will be useful to me in theorising the dysconscious effects of ableism in society.

As I stated earlier, there are diverse aspects of my identity that rise to the fore according to particular situations. At the centre of my self-perception now as a researcher is the identity that I have struggled to incorporate: that of myself as disabled. This influences the whole of my research: from the subject I have chosen; the methods I will be using; to the questions I will be asking of my participants. I became disabled through a road traffic accident in which I sustained a traumatic brain injury; cognitive difficulties arising from that; fractures to my neck, collarbones, and ribs; and a punctured lung. I underwent several surgeries to attempt to rectify the paralysis of my vocal cord caused by the incubation, and my right arm is still virtually paralysed.

Another key influence on my particular standpoint is my past experience as a humanistic counsellor. This has provided me with the urge to understand people, the motives that undergird their actions and how their environment impacts upon and feeds into their psycho-emotional perceptions of self-worth and self-esteem. This has undoubtedly influenced the main focus of my research, which contemplates the relationship between the psyche and society.

I will be consistently reflecting and considering how and why my particular standpoint mirrors a certain perception of society. I will be unapologetically subjective in my research: objectivity is not something that I think any researcher can claim to portray. Sadly this inevitably means that I will miss certain things; certain viewpoints that I have not considered. I am inescapably entangled in the world that I will be analysing, and see no use in trying to set myself free. Rather, I see huge benefits in seeking further entanglement.

1.4 Theoretical Orientations

I will now proceed to outline the major theoretical positions that have been most influential to me and evaluate them on their usefulness in theorising ableism. These include a consideration of: Studies in Ableism (SiA) (Campbell, 2009); social constructionism; phenomenology; critical social psychoanalysis; Crip theory (McRuer, 2006) and postconventionalist theories.

1.4a Studies in Ableism

This is the overarching theoretical orientation in this programme of research and I shall thus explore this concept in more depth in Chapter Two, but I will give an overview of its use as an operational concept here. Instead of focusing on disability and how disability is maintained, Studies in Ableism (SiA) centres on taken-for-granted notions of the ‘ability’ to which disability is compared, and relies on an unacknowledged commonality to which we are all attuned. SiA goes beyond that, however, to implicate all of us in our way of ‘thinking about bodies, wholeness, permeability and how certain clusters of people are en-abled via valued entitlements’ (Campbell, 2009:5). Following Fiona Kumari Campbell in her recent work ‘Precision ableism: a studies in ableism approach to developing histories of disability and abledment’ (2019), she proposes that Studies in Ableism attempt to identify the nuances; the borders; the in-betweenness (or what she terms as *aporias* (Campbell, 2019:138) of the practices and processes of the world we live in. The very idea of ‘ability’ needs to be examined, for example in the ways in which value is attributed to certain populations. This then gives rise to questions around how this prioritisation is nourished and preserved. SiA as a research methodology incorporates analysis of ableist systems; the ‘differentiation, ranking, negation, notification and prioritization of sentient life’ (Campbell, 2017:.287-288).

1.4b Social Constructionism

Social constructionism is concerned with the nature and structure of knowledge, and how it comes to be that some forms of knowledge have significantly more power and influence over society than others. The ableist tendencies inferred with the social construction of disability lead us inevitably to a discussion of the social construction of *ability*. The social production and representation of disabled people has led some researchers in the field of critical disability studies (notable examples include Campbell (2003; 2008); Goodley (2014), Loja et al. (2013); and Wolbring, (2008; 2012) to interrogate the supposed binary opposite: the able-bodied. If ‘being disabled’ is a socially ascribed construct, it follows that the Other, being ‘able-bodied’, is also a socially engineered and generated construct. I argue that this engineering has become

more or less invisible to the general population of Western society due to its hegemonic nature. With the acceptance that this is ‘just the way things are’, ‘ablebodiedness’ has become a largely unacknowledged and uncontested ideology.

The interrogation of the ‘fallacy of the competent, able body’ (Daniels, 2013) represents a new frontier in disability studies, and concerns itself with an examination of the production and maintenance of ableness. This is a tricky manoeuvre, as the values and principles that this phenomenon contains have become so accepted and orthodox that it has seemed preposterous to question them. Take the concept of productivity, for example. It is widely accepted as a given that high levels of production are a necessity in any job, without giving consideration to the capitalist ideology that spawned this conception. This ranking of individuals according to levels of productivity in effect creates *in*-ability, by measuring it with ability. Each person is measured against and their value calibrated according to an idealised notion of ‘able-bodied-productivity’. As Wolbring (2008) observed, the favouritism of abilities like productiveness over more benevolent attributes like kindness and compassion, is historically and ideologically created; it is a social construct.

It is this phenomenon that I will endeavour to explore. The idea that the only type of citizen worthy of value is the autonomous, responsible, capable citizen have been with us since the Enlightenment period (Gergen, 1999; Beckett, 2006). With the rise of capitalism came the rise of individualism (Daniels, 2013) and the theories of the self associated with it, namely that human beings are able to influence and shape their own destiny. This theory of self-determination suggests, then, that all knowledge, power or social status is equally reachable, achievable and realisable to all. Social constructionist theories provide an insightful means of extrapolating and dividing fact from fiction, enabling us to view ‘reality’ as a series of established social creations. Our responsibility to these interpretations of social thought is to look at the different ways that they function in the world. Compulsory able-bodiedness (McRuer, 2003) and the normalising tendencies associated with it, can be said to underpin an ideology of neoliberalism, which has its basis in humanist thought (which, again, presumes the autonomous, free, rational human subject). Thus, as Elizabeth Adams St. Pierre (2000) identifies, the disentanglement from the concepts of humanism are notoriously complex.

...this is an enormously difficult task, since the language, practices and effects of humanism have been operating for centuries, envelop us every moment and have become ‘natural’. Humanism is the air we breathe, the language we speak, the shape of the homes we live in, the relations we are able to have with others, the politics we

practice, the map that locates us on the earth, the futures we can imagine, the limits of our pleasures. Humanism is everywhere, overwhelming in its totality; and, since it is so natural, it is difficult to watch it work.

(St. Pierre, 2000:478)

As Campbell (2001) exposed, the concepts and workings of ableism and the individualistic, humanist way of thinking have pervaded so deeply into the foundations of society that the project of uncovering it will not be easy.

The links between humanism, individualism and ableism are fascinating, and can be seen most clearly in the operation of schools, where ‘the vocabulary of standardisation and a grammar of design (are) sanctioned and sustained by particular social practices’ (Goodley, 2011:57). This is where the key goals of humanism – creating, as we shall see, the individual with the ‘actualising tendency’ – underpin and fuse with the key goals of individualism and capitalism – producing self-sufficient, autonomous individuals who will be willing to ‘work themselves to wreck and ruin’ (Goodley, 2014:65) under the misguided notion that this is what they *need* to do in order to be happy – intermesh and congeal. Individuals are squeezed and moulded to fit this ideology; ableism can be seen as a direct consequence of this squeezing. This is combined with an ideological white-washing (pun intended), where the internal processes of these oppressive practices have become so naturalised and authoritarian that the very purpose of questioning them seems pointless. It is this element that is the most relevant to my study: the systematic (often dysconscious) privileging of some over others. In current ideology it is common to be compared and contrasted with what we are not, for example man/woman; normal/abnormal; self/other; and so on (Goodley, 2011:105). Although it is useful theoretically to have these binary distinctions (as it opens up a space with which to explore these rhetorical devices), I have argued elsewhere (Daniels, 2013) that it is the need for society to have such distinctions in place, *uncritically*, that creates divisions, fracturing our already fragile society. The ‘violence of binarism’ (Goodley, 2014:58) is ‘a structure upon which the authority and consciousness of the dominant is imagined and maintained through the constant negation of the other’ (Goodley, 2014:58) – in this case, the ‘able-body’ is revered and endorsed through the subordination and inconsideration of the ‘disabled body’. We can see this in everyday settings in the way that society is constructed with a certain idealised, normative, able-bodied, adult, male citizen in mind. Consider, for example, the scarcity of provision of spaces in which a woman can breastfeed her baby, or toilets that are the right size for children. Foucault’s notion of *biopower* is essential here; this describes the use of ‘statistics, demographics, assessment,

education, measurement and surveillance' (Goodley 2011:106) to keep the general population in check; to ensure that we police *ourselves* in relation to how closely we 'fit' to the idealised subject.

1.4c Biopower

Biopower, in the words of Paul Rabinow and Nikolas Rose (2006)

...entails one or more truth discourses about the 'vital' character of living human beings; an array of authorities considered competent to speak that truth; strategies for intervention upon collective existence in the name of life and health; and modes of subjectification in which individuals work on themselves in the name of individual or collective life and health.

(Rabinow& Rose, 2006:195).

It is no longer good enough, for example, for a disabled person to explain the difficulties that she has with day-to-day functioning. It must be ratified by a doctor, someone 'considered competent to speak that truth'. By enforcing normalcy (Davis, 1995) through the manipulation of society to aspire to conform to or emulate the norm, it is theorised that governments have succeeded in generating a docile, pliable proletariat. As Moser (2000) identifies, however,

This construction, the norm, is almost identical to what we have learnt to call 'the modern, liberal subject': the independent, autonomous centred, singular, verbal and therefore competent subject. But this idea has already been deconstructed and revealed for what it really is: people are not the master in their own houses (or even their own bodies) in this way. They do not have the power to create either themselves or history. There is probably no single person who can live up to the norm against which disabled people are generally measured.

(Moser, 2000:209)

As Donna Haraway (2003), whilst discussing the importance of recognising and deconstructing oppression, eloquently notes: 'This is the gaze that mythically inscribes all the marked bodies that makes the unmarked category claim the power to see and not be seen, to represent whilst escaping representation. This gaze signifies the unmarked categories of man and white' (Haraway, 2003:26). This almost parallels the project of ableism; to dismantle, de-mystify and explicate the practices and procedures of ableist normativity (Campbell, 2008). Under the lens of Studies in Ableism (SiA), we can see that the notion of the autonomous, rational, able-bodied, capable citizen is revealed as being not neutral, but instead ideologically created. The 'self-contained, authentic subject conceived by humanism to be discoverable below a veneer of cultural and ideological overlay is in reality a construct of that very humanist discourse' (Alcoff, 1988:415).

The concept of biopower is used within this programme of research to uncover the dysconscious ways in which the mythical ‘norm’ is promoted as a site of desire. Why do we want to be unseen? What are the consequences of being seen? How are we policed? This will be a particular focus of Project Two: interrogating ableism in motherhood. To what extent are disabled mothers themselves implicated in the production of ableist aspirations? This concept is also useful in examining ableism in education (Project One). The notion of self-entrepreneurship in achieving and maintaining high grades, for example, is dredged up and probed to expel the ableist tendencies lurking within its grasp. How do we assess ourselves in relation to standardised concepts of ‘good’ and ‘bad’? How have educational institutions controlled and reinforced these concepts, and how have they merged and fused onto the psyches of disabled students, altering their self-perceptions? What modes of subjectification are used to propel us to perpetuate these rules? These are some of the questions that the concept of ‘biopower’ will help me to address in this programme of research.

1.4d Phenomenology

Phenomenology as its most basic can be described as the study of lived experience; the phenomena of being in the world. This has particular benefits to the study of the complex and intricate relationship between society and the psyche, and therefore this thesis. Hughes & Paterson, (1997) Hughes, (2004) and St. Pierre (2012) in particular have used this approach to shed light on both the inner and outer worlds of experience of disability. The body, according to proponents of this view, is *the* site of interaction of the self and society. It is a theory which seeks to understand reality as it is interpreted through and by human consciousness, and by the effect that these interpretations have on this reality. Paterson and Hughes (1999) criticised the disability movement as being too focused on the disabling barriers in the environment and thus ignoring the emotions that come from discrimination and disabling attitudes. Phenomenology provides fertile ground for the incorporation of the body, as it holds it as a fundamental location on which the interactions between self and society are ultimately played out (Goodley & Runswick-Cole, 2013). Paterson and Hughes (1999:603) point out that one of the central tenets of phenomenology from a disability studies perspective is that ‘the disabling and disabling socio-spatial environment produces a vivid, but unwanted consciousness of one’s impaired body’. For these reasons, the reader can expect to see a peppering of phenomenological thought flavouring this programme of research.

1.4e Critical Social Psychoanalysis

I draw the reader's attention back to the initial research question that I will be seeking to address, that of the complex interrelationship between the psyche and society (which phenomenological thought can help to uncover). What follows is an exploration of how the field of critical social psychoanalysis also can be adopted to facilitate and give voice to the inner murmurs of the (often) heterogeneous and conflicted self.

Critical social psychoanalysis attempts to modify the dyadic inclination to view the psychological and the social 'selves' as separate, isolated fields, instead preferring to view them as being in an ever-complex relationship, both fusing and changing together (Ryan, 2001). This represents a fundamental difference in ontology compared with the humanistic representation of the self. I argue that the conception of who we are is always in a state of flux, from moment to moment and is dependent upon our interaction with others. We construct ourselves in response to our interactions with others and within our internal conversations. As John Shotter (1997:12) expresses it, 'The things supposedly in our 'inner' lives are to be found not within us as individuals, but in the momentary relational spaces occurring between ourselves and another or otherness in our surroundings'. This view is at odds with the humanistic version of the self. The 'self' contained in humanism, which I view as being synonymous with individualism, is a rational, autonomous, self-determined individual, living as a separate entity, 'discoverable beneath a veneer of cultural and ideological overlay' (Alcoff, 1988:415, cited in Ryan, 2001:23). In this view, there is a 'true', never changing self that is bombarded with the burdens of daily living, but through the process of 'talking therapy', can be rediscovered, unburdened and strive for the 'actualising tendency' he (always a he) was intended for. I was trained in humanistic counselling, and worked as a therapist for a number of years and in that training, we were strongly encouraged to view life, and the journey of life as a series of greater or lesser attacks on our 'true' self, which I envisioned as a plant, always finding a way through the cracks. This represented the 'actualising tendency' of all things, and to me was inherently optimistic. The message seemed to be, 'no matter how much of a pickle you find yourself in, you alone have the power to find a way out of it'. This, at times, was a source of inspiration to me and I must tell you, I struggle to shake that out of me, until I think of the lives of people, like me, who cannot miraculously 'get better', who cannot, *through the power of their minds*, transform their lives in such a way that we are free from the 'burdens' inflicted upon us once and for all.

Thus, if a person finds themselves in unfavourable circumstances, it must be because they have not tried hard enough. The problem with this way of thinking is it essentially blames the person

for any situation that they find themselves in, without taking sufficient account of extenuating circumstances. This has particular concerns for disabled people. Indeed, Abraham Maslow, who has been credited with creating aspects of humanistic theory, has been accused of creating a ‘new and seductive Social Darwinism that is used to justify a capitalistic system with its privileges and practices for its powerful elite’ (Shaw & Colimore, 1988:56, cited in Pearson & Podeschi, 1999:45). Giving a critical eye to the nature of humanism would suggest that this way of being contributes greatly to the inequalities in society. Its time has come.

The roots of psychoanalysis can be said to be troublesome; nonetheless I believe it may have something valuable to say and should be included in the conversation.

Psychology’s relationship with Disability

We have already briefly covered the frantic desire for normalcy that arguably affects the vast majority of Western society and how that equates with individualism and capitalism. Psychology viewed deviation from this mythical norm as a sign of personal deficiency, which has been decontextualised and located squarely within the individual. As this has become accepted, this has profound implications for the developing child in an educational setting. As I referred to earlier, the individual of contemporary society is encouraged (to put it mildly) to talk about their problems, to share their innermost troubles. This, Goodley (2011:77) notes, leads to ‘psychological interventions to cure mental illness, improve education, stamp out prejudice and create fulfilling lives’. Behind this seemingly benign motivation lurks a more sinister inclination; by assessing people’s inner thoughts, psychologists and other agents contracted to maintain social order are able to signify some people as more rational, self-determined and therefore more ‘worthy’ than others. This psychologisation effectively reduces ‘problems’ to the individual level. Therefore, we can say that mainstream psychology is essentially conservative in nature, as it aims to maintain the status quo and thus maintain unjust and oppressive conditions.

‘So where is this leading?’ I hear the reader ask. ‘How on earth can psychoanalysis help in the analysis of ableist practices, if it was complicit in their production?’ Traditional psychoanalysis is based upon a largely medical view of disability, therefore treating disabled people as objects; research is *on* disabled people rather than *with*. It is no wonder, then, that disability studies has an uneasy relationship with psychoanalysis. *Critical* social psychoanalysis, however, can be used to enhance disability studies in various ways, which will now be considered.

Tools of critical social psychoanalysis

Sigmund Freud, whatever other failings he (definitely) had, provided us with a way of unearthing the repressed idealisations and fragmentations of the unconscious (Goodley, 2013). Freud postulated that there was a vast field of the human mind that was inaccessible to us on a conscious level, and that we all employed defence mechanisms in order to shield us away from potentially hurtful or frightening things that we feel that we need to be protected from. In doing this, we unconsciously distort or disavow parts of reality (Watermeyer, 2013). Again, this explanation could risk individualising the enhanced understandings produced, however a nuanced application of the insights ‘illuminate the unconscious underpinnings of social structures and intergroup behaviour, exploring how political and psychological realities constitute one another’ (Watermeyer, 2013:52). Extending this concept into a disability-related focus impels us to provide a critical deconstruction of the hegemonic attitude to disability, ‘reveal(ing) those ableist ideals and disablist tendencies of the collective unconscious’ (Goodley, 2013:55). This allows us greater scope with which to analyse the ‘psychopathology of the normals’ (Goodley, 2013). To use Goodley again here, social psychoanalysis can aid us in our attempts to deconstruct the non-disabled subject, particularly

the ways in which non-disabled people and disablist culture symbolise, characterise, construct, gaze at, project, split off, react, repress and direct images of impairment and disability in ways that subjugate, and at times, terrorise disabled people whilst upholding the precarious autonomy of non-disabled people.

(Goodley, 2010:2).

Moreover, the ‘inability’ to accept a subordinated social position is held by the non-disabled as evidence of denial. Disabled people are expected by the majority (non-disabled) world to emphasise their capabilities, whilst *constantly* being forced to be aware of their limitations and dependence on others. The focus is always on what we *cannot* do. This is not expected in the able-bodied world. We are continually being made to feel lacking, incompetent and in-valid, however far from the truth that observation really is, and however much the non-disabled’s claim it isn’t so. Clearly, there are stale remnants of distaste in relation to disabled bodies plaguing the minds of the (socially and psychologically constructed) able-bodied world. A social psychoanalytic approach maintains that we cannot be effective in challenging disablist culture solely by focusing on the conscious thoughts of this able-bodied world; we need to ‘uncover societal, political and cultural knowledge/practices that impact upon the development of the unconscious/conscious and the psyche’ (Goodley, 2011:719). By applying a critical social psychoanalytic framework to the analysis of ableism, I am hoping to uncover nuanced

ways in which the practices and procedures of ableism continue, and thus conceive of alternative ways in which these processes may be disrupted.

Lacan's formulation of castration to signify loss can be used to extrapolate the non-disabled's feelings around/aversion to people with impairments. The presence of 'impaired bodies' serves as a stark reminder to the non-disabled of their own mortality, and psychoanalysis can help us to understand the ways in which the ego strives to avoid confrontation with its own mortality, pushing or projecting this troubling reminder into the external world. This process can be referred to as 'othering' – the subconscious removal of that which is disconcerting, distancing ourselves from that which we do not want to own. This knowledge of lack must be repressed, or held to be a part of an-Other's existence, not our own (Wilton, 2003). As Wilton (2003) identifies, it is expected that disabled people will inevitably mourn the loss associated with the (medical interpretation) of their 'loss'. He suggests that when non-disabled people see what they perceive to be 'lack' in another, they expect a mourning process to occur, and

...when disabled people, either unintentionally or purposefully, subvert dominant constructions of disability, these encounters have the capacity to produce what Lacan conceptualises as 'the lack of the support of the lack' (Copjec 1991:27) – an uncanny moment that reveals the limits of the symbolic order, and destabilises the dividing line between non-disabled and disabled, throwing the integrity of the able-body into doubt.

(Wilton, 2003:381).

One of the fundamental insights of social psychoanalysis, Wilton maintains, is the imaginative and desperate ways in which the fallacy of the competent, self-determined, self-actualising, energetic able-body is maintained through comparison and constant negation of the Other. Psychoanalysis can also offer a more forgiving and compassionate reaction to the way in which oppression is enacted; Wilton (2003) suggests that the way in which people react to disability is often not in their conscious control, but is effectively hidden from them in their unconscious. This would suggest that forms of oppression could be relieved through the education of the non-disabled, and perhaps by increased integration with disabled people. Goodley (2014) suggests a range of ways in which the pathology of 'these poor normals' can be treated; a tongue-in-cheek method of implicating their bizarre behaviour in response to disabled bodies. He proposes that they receive therapy to deal with their reaction to disability, stating that it is because the normals are so caught up in the fantasy of productivity and the fallacy of the 'able-body' that they fail to see the possibilities and potentialities of abnormalcy. This study seeks to centre these psycho-emotional dimensions of ableism as they have a profound effect on the relationship between society and the psyche.

Incorporating Psycho-emotional aspects of Disability

There may be a danger through ignoring the psychological that the belief may be reinforced that a layer of disabled people's lived experience is illegitimate and to be obscured – even rendered inadmissible – if there is to be any hope of real movement towards an equitable society...It has always been part of disabled people's oppression that their own personal feelings and struggles have been seen as epiphenomenal and secondary to the objective reality of their impairments.

(Watermeyer & Schwartz, 2008:600).

Watermeyer & Schwartz (2008) here echo the urge for a model of disability that incorporates the psychological and emotional effects of disability – discrimination against disabled people - as a *product* of ableism (Goodley, 2014). They are arguing for these often monumental feelings to be given credence and allow a space in which they can be heard.

Broadly speaking, the Medical Model view of disability is characterised by a scientific and medical (hence its name) view of impairment, stating that disability is an inescapable consequence of a medical condition, and that the individual concerned suffers a disruption in a physiological, psychological or cognitive way. It is a deficit-orientated description that denotes that disabled people are limited in their ability to perform functional activities. From this perspective, disability is a tragedy inflicted on passive individuals who therefore need to be pitied. The Medical Model view sees disability by and large as an individual problem in need of individual solutions. The solution to the disability problem is to 'fix' the disabled person and 'normalise' them by, for example, offering them accommodations. Fundamentally, society remains unchanged by this process. A Social Model perspective, however, sees disability as the result of barriers to access in the environment, not as caused by the impairment. These barriers are the consequences of a lack of foresight in social organisation. Therefore, society needs to make vast social, cultural, structural, and economic changes in order to include disabled people.

Whilst the Social Model was incredibly proactive in signalling the injustices promulgated upon disabled people, it also had the unintentional effect of silencing many, as Watermeyer & Schwartz (2008) make reference to in the quotation above. I can well appreciate the need amongst its contributors to discourage the expression of personal experiences lest they become engulfed by the 'tragic' stereotype of disability and thus feed in to the medicalised, flawed and ultimately individualised version of disabled corporeality. The Social Model movement is, arguably, slowly becoming incorporated into the mind-set of policy makers, however begrudgingly. But as Watermeyer and Schwartz (2008) note here, the omission of disabled

people's emotional reactions and responses to disability and experiences of disablism could lead to greater difficulties and experiences of alienation. There needs to be a place within the theory of disability to recognise what Reeve (2002) terms as 'the barriers in here' as well as explicitly recognising and challenging the barriers 'out there'. Carol Thomas (1999) has rectified this somewhat with her new definition of disability; 'Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing' (Thomas 1999:60). This goes some way into incorporating the possible effects that acts such as stares, snubs or sometimes outright hostility can have on the emotional and/or psychological states of people with perceived impairments.

Reeve (2002) uses a Foucauldian framework with which to analyse 'the ways in which 'regimes of truth' about disabled bodies affect their governance and control' (Reeve, 2002:496). The experience of being stared, for most people, at can induce feelings of shame, anxiety, humiliation and often anger in the object of the gaze. This suggests a form of power play, with the observer accruing knowledge and a sense of authority over the observed. This, Reeve advances, is most often seen in the treatment of disabled people by the medical world and has the capacity to make people feel 'rejected and worthless' (Reeve, 2002:498). Reeve also points to the ways in which this 'gaze' can manifest itself in everyday social interactions, making the disabled body somehow 'public property'. I have previously (Daniels, 2013) cited many examples of how random strangers feel it is their *right* to interrogate exactly how I've ended up with such a 'weird' voice, with no concern as to how personal those answers may be or how I might feel after sharing them. The fear associated with rejection from having a voice that is non-normative has dissuaded me from many activities, including giving presentations, speaking to strangers, speaking out in lectures or seminars, especially in a noisy room. I avoid putting myself in positions where the lack embodied in my voice will single me out. The message (or, my perception of the message) that people are continually trying to convey to me is that *it is not ok* to have an unconventional voice. I have internalised this message, which has meant a significant loss, especially related to my social life. This is the area where I struggle to remain political; these losses are individual, and this tumbles me back down into the medical, personal 'loss' model of disability as I battle to manage these questions in a way that would be more personally empowering. As Morris (1991:25) concurs: 'It is not only physical limitations that restrict us to our homes and those whom we know. It is the knowledge that each entry into the public world will be dominated by stares, by condescension, by pity and by hostility'. In

writing this, I feel a great sense of lethargy and hopelessness, and a need to crawl under the covers of my comfortable bed or to seek comfort in the company of loved ones. It is important to note, as Reeve does, that not all disabled people will feel, or will have the same strength of feeling from this form of psycho-emotional disablism, but this has the potential to make disabled people feel, *to their very core*, in-valid. This is the main reason I will be focusing on this particular aspect of disablism and the complex relationship with ableist tendencies in my research.

Disavowal – ‘splitting’ the subject

My interpretation of the concept of disavowal is the process by which a disabled person disowns, or disavows, parts of herself that she is ashamed of. She consciously and unconsciously denies her relationship to disability in an effort to ally herself more snugly with the dominant group, thus rejecting the parts of herself that do not ‘fit’ with the ideal that the dominant culture desires. This can lead to a ‘splitting’ of oneself; an ontological, psychological and emotional dilemma that has the potential to wreak havoc on the self-perception of disabled people. As Campbell (2008:8), citing Kuussisto (1998:7) reports;

Raised to know I was blind but taught to disavow it, I grew bent over like the dry tinder grass. I couldn’t stand up proudly, nor could I retreat. I reflected my mother’s complex bravery and denial and marched everywhere at dizzying speeds without a cane. Still, I remained ashamed of my blind self, that blackened [sic] dolmen.

This perspective underscores the potential consequences of disavowing disability. The concept of disavowal as I have defined it here will be used as a social psychoanalytical resource in the analysis of this programme of research. As noted in my acknowledgements, the complexities of welcoming the parts of oneself that the dominant culture emphatically rejects may result in ontological invalidation. More discussion will be given to this complexity throughout this programme of research.

Emotional labour

The term ‘emotional labour’ is a poignant one, loaded with meaning. It was a term first coined by Arlie Hochschild in 1983 to refer to the added emotional work in regulating emotional expression and conforming to expected cultural norms. Emotional labour refers to the effort that one displays when ‘one is required to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind to others’ (Hochschild, 1983:7). As I will show in this thesis, disabled people are required to do this on a regular basis. Liddiard (2014:4) for instance, cites several examples of where disabled people are required to undertake

additional labour; ‘Types of work included hiding impairment and its effects; being extra productive to counter employers’ negative assumptions; and carrying out informal teaching around disability issues for co-workers and managers (Church et al 2007)’. Goodley (2010; 2018) has also incorporated this concept into his work, focusing on the performances disabled people are expected to give in order to satisfy non-disabled cultural expectations. Indeed, as Goodley, Liddiard & Lawthom (2018:200) perceptively state,

Emotions are corporeal thoughts, embodied processes, imbricated with social values and frequently involved in preserving social bonds, social rules and display of behaviour (Williams 2003, 519–520). Hochschild’s concept of emotional labour refers to those times when the self acts in ways that fit the expectations of others.

This relational facet of emotional labour speaks to the analysis of this programme of research in particular, and I will use it to address the ways in which disabled people are worn out by these processes of normalisation, negotiation, disavowal, and the splitting of oneself.

This programme of research, however, is envisioned as more than a critique of disabled people’s current position within western societies. It is intended to open up a reflective space wherein the existence of disabled people can be appreciated as offering a different path; an alternative way of living life.

1.4f Crip Theory

Crip Theory, as envisioned by Robert McRuer (2006), is a theory which seeks to unsettle normative thinking, re-appropriating previously derogatory words (such as ‘Crip’) and reclaiming them in ways that signify power and defiance. As Hutcheon & Wolbring (2013:n.p) note, ‘To ‘crip’ is not just a conceptual or academic exercise of critique and disruption — it unfolds in the lived realities, daily practices, and performed identities of individuals and groups as they preserve Self and community’. Out of Crip theory springs the notion of ‘Crip time’. My use of this concept is to signify a malleable, morphing fluidity of standardised notions of time as they have been widely applied to much of Western society (Kafer, 2013). In the words of Ellen Samuels (2017), Crip time allows folk to define their own normal. It seeks to uncover the unconscious privilege of occupying culture standard time (Michalko, 2002). Crip time is not straightforward; it is not a neat concept encompassing the provision of more clock time to disabled people. Rather, as Samuels (2017:3) puts it,

Crip time is broken time. It requires us to break in our bodies and minds to new rhythms, new patterns of thinking and feeling and moving through the world. It forces us to take breaks, even when we don't want to, even when we want to keep going, to move ahead.

It insists that we listen to our bodyminds *so* closely, *so* attentively, in a culture that tells us to divide the two and push the body away from us while also pushing it beyond its limits. Crip time means listening to the broken languages of our bodies, translating them, honoring their words.

This means honouring the depths of feeling encountered by society attempting to propel a person to meet the demands scripted by cultural conventions, embracing the power contained in these feelings and using it to subvert and rally against these narrow codes of conduct to create enlivening possibilities. This opening up of opportunities is furthered in the next theoretical approach.

1.4g Postconventionalist theories

Another multifaceted and pliable way of looking at interrogating ableism is through the theoretical concepts of postconventionalism. This approach can incorporate elements of social psychoanalysis, Studies in Ableism, and social constructionism. Postconventionalist theories resist defining disability; instead appreciating the fluidity and slipperiness of its nature. I shall invoke Goodley again here, using his delivery at a symposium at Lancaster University in November 2011 to provide a succinct explanation of postconventional theories and how they can be mobilised to help our cause: 'Postconventionalist theories...aim to reframe the disabled bodies/minds along the lines of capacity, potential, interconnection and possibility' (Goodley, 2011:65). Postconventional theories take on board the deconstructive elements of social constructionism, critical social psychoanalysis and SiA and then go further to ask about the possibilities of disability; an essential element in offering an alternative life path.

Through this perspective, we can turn a critical eye onto the forms of life and the bodies that are valued, enabling unique perspectives on the workings of society. From our perspective on the outside looking in, disabled people are in a privileged position to observe and provide critique on the principles and beliefs twisted and entwined with perceptions of the 'good life' and the 'valuable citizen'. Postconventional language uses terms such as 'interconnectedness', 'merge', 'connectivity', 'fluidity', 'linkage' and 'process of becoming' (Shildrick & Price, 2006) to identify the possibilities of moving into a world in which the 'destabilisation of existing hierarchies and the collapse of any one normative standard' (Shildrick & Price, 2006:2) is imaginable. My understanding of postconventionalist theories is that the fundamental aim is to recognise, account for and celebrate difference, without giving in to the tendency to hierarchize.

Einstein & Shildrick (2009) note that one of the defining features of postconventional approaches is the notion of embodiment to replace the Cartesian mind/body split. The notion of embodiment goes further, to incorporate the merging and interrelation between the entire person and the external world in which no single component has independent meaning, postulating that 'knowledge is always fragmented and dispersed in a series of conflicting discourses that will never resolve into a unified whole' (Einstein & Shildrick, 2009:295). They acknowledge that a real acceptance of the 'messiness' of the human body would necessitate a certain comfortableness in the face of ambiguity, something that a lot of people may struggle with. This requires an 'epistemology of ignorance... an openness to the risk of the unknown... and a willingness to be unsettled' (Einstein & Shildrick, 2009:293). In such a permeable position, then, the assumption of a single fixed, ideal, unitary and unchanging able-bodied 'norm' is questionable and represents an outdated ideology. This too questions any unified understandings of 'ability'. The re-siting of health and disability as 'practices of regulation and control that produce the bodies they govern' (Shildrick & Price, 1996:99) allows us further opportunity to explore these very practices, uprooting the ableism that lurks in their foundations.

If the formally essential and fundamental notion of autonomy was placed into question, what possibilities would be opened up? If we dispel this myth of sovereignty and self-reliance, and instead align more with the intention of creating further pathways for integration and interconnectedness, we may discover new and innovative ways of becoming. In other words, by destabilising and challenging conventional practices, hegemonic beliefs, structures and institutions, what we are left with is fresh ways of imagining the role(s) of humans, governance, education systems, science, and technology and so on. This understanding of mutuality and reciprocity harmonises well with studies in ableism, energising the possibilities held within them. It also touches on the beneficial aspects of social psychoanalysis, displaying an inherent mistrust of the 'centrality of the individual' (Goodley, 2014:63) as an autonomous, separate entity, with a self-owned body, separate from the mind, presenting alternative ways of thinking about *what it means to be human*.

The tricky part ahead of me now is weaving these theoretical impulses together to form a cohesive, holistic theory that envelops all these theories. Perhaps it is not possible (or advisable) to do this without dulling the razor-sharp edges and the analytical tensions that each theory exposes, each stripping bare different elements that congeal to form ableism. Each theoretical alliance will have its story to tell, and I intend to embrace the multifocal nature of

this in my study. By employing a range of theoretical approaches, I am aiming to weave a patchwork quilt of varying knowledge positions, allowing me access to a myriad of voices. I will then wrap this quilt around myself, listening attentively to the whisper of the bountiful voices, welcoming the array of possibilities that this provokes.

CHAPTER TWO: SETTING THE STAGE

2.1 Overview

This chapter will set out the programme of research that the reader will be presented with in this thesis. It rests upon two studies, conducted in an effort to tease out instances of ableism in practice. The overall aim of this programme of research is to identify the psychological and emotional consequences of ableism in society, with a particular focus on education and motherhood, and therefore the reader needs to be enlightened as to my interpretation of the concept of ‘ableism’ and why I feel that it is a powerful force that needs interrogating. Even this simple statement belies the extent of the task ahead of me; as ableism is so ingrained in the foundations of western society, pervading everything we do, it is not just a case of scraping away the top layer of societal functioning and saying, ‘there, that’s ableism; now let us change our practices to relieve the oppression’. I argue that it is deeply entrenched in the mind-sets of sometimes even disabled people themselves, forcing psychological and emotional wounds that are open to further affliction.

The first section of this chapter will think through the epistemology of ableism, defining what is implied by the term and describing the nuances of its application within this thesis. The next section will consider the logics of ableism, for example whether it is possible to celebrate success without replicating the philosophy of ableism. The subsequent section of this chapter will address the ways in which the concept of ableism will be revisited, and used as a conceptual tool for interrogating the preferential treatment of non-disabled people. I will consider ableism in terms of its application to three core areas: education; research methods; and mothering ideology. Ableism, thus, will be a defining feature of both research projects, endeavouring to exemplify the dysconscious ways in which this vicious phenomenon permeates all of our lives.

2.2 The Epistemology of Ableism

Ableism as a concept is, in some ways, a slippery one to define. The dangers of the act of defining it in itself will be explored in more detail at a later stage within this section, but for now I feel it would be useful to begin with a broad outline of the ideas encapsulated in this approach. I will begin with my understanding of the term, which is informed by a thorough reading of the books, articles and other texts on the subject by Campbell (2003; 2008; 2008b), Cherney (2011), Davis (1995; 2005), Goodley (2011; 2014), Harpur (2012), Hehir (2007), Ferrier and Muller (2008), Smith (2004) and Wolbring (2008; 2008b). I will then attempt to illustrate how concepts of ableism differ from and bleed into concepts of disablism, and

elucidate how the study of ableism can contribute to disability studies and the disability movement as a whole. My final endeavour in this introductory section will be to exemplify how ableism can be perpetuated through internalisation.

2.2a Tentative Definitions of Ableism

Ableism has been defined by many different authors, theorists, disabled advocates and allies, all with slightly different interpretations of the term with a view to using this notion to further arguments in a variety of ways. My understanding of the purpose of this re-focusing of the debate has been to ‘out’ the ‘able’ – by that I mean to interrogate the subjectivities, values and characteristics bound up in the seemingly benign notion of abledness. Following Wolbring (2008), the processes of ableism can be defined as a ‘favouritism of abilities’ – reflecting ‘the sentiment of certain social groups and social structures to cherish and promote certain abilities such as productivity and competitiveness over others such as empathy, compassion and kindness’ (Wolbring, 2012:3). This, he states, leads to those who apparently do not possess these apparently fundamental attributes being labelled as deficient, lacking and therefore justifiably ‘othered’ by society. What is left unquestioned is why these attributes are so prized and revered, and intrinsically used as acceptable measures of worth. Cherney (2011) adopts a philosophical stance on ableism and takes this point further, postulating:

As the capacities privileged, rewarded and normalised by cultural systems that depend on their presence and performance, ‘abilities’ are thoroughly social constructs communicated rhetorically. Knowing them as such reverses the ableist episteme that ‘body is able’, opening to critique any claim that some skill should be favoured over others.

(Cherney, 2011:6)

Ableism can be said to concern itself with categorising, ranking and measuring people on a continuum according to how far and to what extent they measure up to a pre-ordained conception of ‘normality’. Cherney (2011) employs Aristotle’s ‘Generation of Animals’, which presents the point of view that ‘normal is natural’, to illustrate the hegemonic acceptance of deviation from the norm as aberration. By assimilating this view of normal being natural as ‘the intended aim of nature’ (Cherney, 2011:8), it is subsequently accepted as ‘truth’ and thus escapes thorough theoretical critique. This notion in itself may be worth unpacking.

The insinuation here is that non-disabled people are the norm, and that disability is an anomalous social and cultural category which needs to be eliminated, segregated or at the very least labelled as dangerous (Smith, 2004). Further, by creating the view of the non-disabled as

the norm, this spawns a hidden ideology, the ‘tyranny of normalcy’ (Davis, 2005) in which all of us are (consciously or unconsciously) assessed. Smith (2004) explicates;

By creating a marginalised other in the form of disability, the privilege of the centre – the normal – becomes hidden from view, and its power and control over society becomes presumptive. Members within the culture cannot even see the centre (the normal) – it is ‘natural, undisputed and unremarked’ (Thompson, 1997:20).

(Smith, 2004:13)

This ideological orientation arguably remains with us to date. The medical gaze effectively invalidates bodies – any bodies – that do not measure up to a fabricated ideal of the ‘norm’. Loja et al. borrow from Campbell’s (2009) work and state that ‘Ableism imposes a corporeal standard, the falling away from which represents the pathway to disability’ (Loja et al., 2013:191).

For Harpur (2012) ableism accentuates the belief that every body will be affected by ability discrimination during their lifetime, and points to the temporality of independence and the shifting nature of ‘normalcy’. He suggests that even a person who is defined (or defines themselves) as having no physical, mental or emotional impairments can be at best only described as being ‘temporarily able-bodied’ (Harpur, 2012:333). Following from Harpur’s work, ability discrimination implies that, for example, a 30 year-old, fit, ‘able-bodied’, productive man would be preferred by employers when compared with a 55 year-old, also productive man with occasional back problems. This underscores the unstable nature of the concept of ability.

This ranking of bodies extends to education, where we can see the workings of ableism permeating the educational landscape, infiltrating it like a creeping, thorny bramble that has stealthily taken root and will not be shifted easily. As Hehir (2007) exemplifies:

An ableist perspective asserts that it is preferable for a child to read print rather than Braille, walk rather than use a wheelchair, spell independently rather than use a spell-checker, read written text rather than listen to a book on tape, and hang out with non-disabled kids rather than other disabled kids.

(Hehir, 2007:8).

This view relates strongly to the perspectives expressed by Cherney (2011) and Wolbring (2008) that certain characteristics and forms of productivity, and how they are enacted in society, shapes how we are deemed to be worthy or unworthy members of the social order. Hehir here is adopting a pedagogical stance to explain the extent of ableism in educational

practice, a stance that I will make substantial use of in my own research, and thus an approach that will be explored extensively in Project One.

Campbell (2008) uses critical race theory as a tool with which to probe the mechanisms of ableism. She uses this tool partly to exemplify the similarities between these two forms of oppression, as both can be used consecutively to deconstruct the unspoken concept of the 'norm' and uncover the hidden ideology undergirding Western society. Smith (2004) concurs:

Disability scholars can learn much about disability and ableism by proposing a corollary to whiteness theories, that is, normal theories, as a way to unpack and dismantle the unspoken language of normative ideologies that create disability as a social category.

(Smith, 2004:1)

Possibly the most profound function of the relationship between race and disability for disability scholars is the dysconsciousness with which oppression occurs; the inability on the part of the oppressors to recognise the oppression itself as discriminatory practices are shielded under the cloak of normalcy. Smith states, '...racisms are a function of the invisibility of whiteness for Whites, a kind of chromatic blindness...' (Smith, 2004:5). This mirrors the difficulty in extrapolating and translating the values and practices of ableism to the able-bodied.

Campbell draws parallels with the often taken-for granted oppression of certain races in society with the rhetorical practices of ableism. The hegemonic acceptance of having a healthy body/mind as a natural desire (well, who would actually *want* to have anything else?) leaves the questioning of which characteristics are valued, and more importantly why, unexplored. This, she suggests, can be countered with the interrogation of 'the production of ableness'. Campbell defines ableism in her early work thus:

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

(Campbell, 2001:44, cited in Campbell, 2008:153).

In her doctoral thesis (2003), Campbell embraces Tom Shakespeare's call for us to 'deconstruct the normality-which-is-to-be-assumed' (Shakespeare, 1999:28) and begin to *speak otherwise* about impairment (Campbell, 2008). She warns us, however, about creating yet another 'grand narrative' in the form of a precise, inflexible definition of ableism as a totalising cultural schema to order and explain knowledge and experience and thus offer one standardised notion

of the truth. For Campbell, the concept of ableism does not have an absolute, narrow meaning; rather ‘...as a conceptual tool ableism transcends levels of governance related to procedures, structure, institutions and values of civil society and locates itself clearly in the arena of genealogies of knowledge’(Campbell, 2003:94). Campbell is situating the concept of ability, disability and ableness as arising from deep within our social and historical collective souls; something that is entrenched in the very foundations of our being. Ableism then is not cited as a system of oppression with one identified ‘enemy’ that requires redress but an intricate system of practices and behaviours that serve to oppress us, that is often painfully borne out of the ontology and epistemology of disabled people themselves. We will return to this point later, but for now I want to offer two more theoretical perspectives on the notion of ableism from Wolbring (2012; 2008) and Goodley (2014).

Wolbring (2008) offers a further definition of ableism:

Ableism is a set of beliefs, processes and practices that produce – based on abilities one exhibits or values – a particular understanding of oneself, one’s body and one’s relationship with others of humanity, other species and the environment, and includes how one is judged by others.

(Wolbring 2006a, 2007 a, b, c, d, cited in Wolbring 2008:253).

This definition already impels us to look further afield in the study of ableism; his concern is that to curtail the debate to solely an able/disabled perspective will limit the possible reaches of this campaign. Wolbring postulates that there are many different faces to ableism; it can be seen in the assumption that women are inherently and inevitably weaker than men, that their judgement is invariably influenced by their emotions and therefore is questionable; it can be seen in racism wherein the supposed behavioural traits of one race is seen to be geared inevitably towards delinquency; it can be seen in casteism wherein one group of people by way of their birth, are seen to possess (or lack) certain inherent qualities.

In his 2008 piece, *The Politics of Ableism*, Wolbring goes on to ruminate on the fine web of intricacies connecting science and technology to the processes of ableism. For example, the increased ability of technology and medicine to combine powers to modify and ‘improve’ the human body can alter our relationships with our own bodies dramatically. Moreover, the obsession with aesthetics and the media lead us to view our bodies in very different, by and large lacking way. This is no longer just an issue for people labelled as disabled, it is a matter of concern for everybody in this never-ending quest for ‘perfection’. The species-typical body is under constant threat. Indeed,

One transhumanised form of ableism is the network of beliefs, processes and practices that perceives improving the human body and functioning beyond species-typical boundaries as essential. The transhumanised version of ableism sees all bodies as limited, defective and in need of constant improvement beyond species-typical boundaries.

(Wolbring, 2008:254).

Whilst there are many positive potential outcomes of transhumanism for disabled people, for example, the creation and amelioration of technology to construct new limbs, my reading of Wolbring here is pointing to the dangers of widening the perceived gap between ‘able’ and ‘lacking’ further.

Finally, arguably the most comprehensive articulation of the term comes from Goodley (2014);

Ableism’s psychological, social, economic, cultural character normatively privileges able-bodiedness; promotes smooth forms of personhood and smooth health; creates space fit for normative citizens; encourages an institutional bias towards autonomous, independent bodies; and lends support to economic and material dependence on neoliberal and hyper-capitalist forms of production.

(Goodley, 2014:21)

Goodley shares with Campbell and Wolbring an urge for us to look beyond the confines of the disability/impairment debate to see the support for our cause that can be garnered from other oppressed groups, and in turn how the study of ableism and disability studies generally can contribute to their struggles.

Additionally, Goodley adds a new dimension to the fray – exposing the neoliberalist ideals bound up in the production of ableism. One of the purposes of ableism, as I understand from his work, is the ‘incubation’ (Goodley, 2014:26) of the ableist citizen. Through a neoliberal ideology, we can see the citizen being moulded to fit predetermined norms, and the ones who do not fit are increasingly left behind. The ideology of individualism states that everyone starts from a level playing field, and the responsibility for success is yours, and yours alone. This results for many in ‘one’s sense of self and value {being} judged in terms of one’s worth in the market economy’ (Goodley, 2014:27). The ultimate concern, therefore, has to be with the educational inclusion of disabled children and young people when the educational institutions are increasingly driven around these competitive, market-based imperatives (Slee, 2013),

Goodley employs the use of the slashed and split term ‘dis/ability’ (Goodley, 2014: xiii) as a tool to explain the duality of understandings denoted by their relationship to each other. This signifies that we cannot effectively study one without looking closely at its assumed polar

opposite; in this case, the chronically under-examined ‘ability’ on one side and ‘lack of ability’ (which has been poked and prodded for decades) on the other. Through studying the connections we can begin to obtain a clearer picture of these two apparently utterly different modes of embodiment, and potentially find paths to acceptance of difference.

Campbell (2013) enhanced her definition of ableism, modifying it to include more nuanced factors in the application of the term;

Ableism is a system of causal relations that produce processes and systems of entitlement and exclusion (Campbell, 2013). This causality fosters conditions of microaggression, internalised ableism and in their jostling, notions of (un)encumbrance. A system of dividing practices; ableism institutes the reification and classification of populations. Ableist systems involve the differentiation, ranking, negation, notification and prioritisation of sentient life (Campbell, 2013).

(Campbell, 2013:2)

This expands the definition to include notions of space and time that are dictated and policed by the ableist imaginary, and postulates on the arbitrariness of this dictation as it is constantly shifting, as ideals of perfected humanness change and intensify.

2.2b Ableism? Disablism? I'm confused... Changing the focus of the debate

Writers such as Campbell, Wolbring and Goodley, among others, have argued candidly about the need for a modification of the phrasing of the debate from centring on disability to centring on ability (Harpur, 2012). The main purpose of this change is, Campbell argues, ‘to reverse, to invert this traditional approach, to shift our gaze and concentrate on what the study of disability tells us about the production, operation and maintenance of ableism’ (Campbell, 2008:1). There has been thus far surprisingly little critique of the concept and meaning of ‘ability’.

Disablism, Campbell sums up, works as ‘a set of assumptions (conscious or unconscious) and practices that promote the differential or unequal treatment of people because of actual or presumed disabilities’ (Campbell, 2008:1.)

All well and good, but these two terms can and I believe has led to some confusion. Whilst doing a cursory internet search for articles relating to the term ‘ableism’, I continually found articles that, on further reading, related more fittingly with my understandings of *disablism*, particularly from American sources. For example, the popular webpage, ‘If I can’t dance, is it still my revolution?’ (Which can be found at www.still.my.revolution.org)

I used to use the term ‘ableism’ to describe oppression against people who are labelled as disabled and/or the idea that disabled people are not as good as non-disabled people. Within the past year or so, however, I have begun using the word ‘disablism’ instead. There are a lot of reasons for this, but the primary one is the fact that ableism implies that this oppression is somehow related to ability – which it is not. Disability is a social category and its label is imposed on certain groups of people because of their perceived characteristics as un(der) productive.

(Withersaj, 2013:1)

This view is echoed on other popular websites, and my concern is that if this confusion over what is implied by the different terms used is not clarified then the potency of the campaign may be hindered. Different cultural understanding of terminology is, to a certain extent, to be expected, but this level of misconception is almost tantamount to a binary opposite. The terms appear to be closely related, and they bleed into one another to a degree, but there is a significant difference.

My understanding of disablism is a term to denote the unfair and inequitable treatment of disabled people and relates to the production of disability. My understanding of ableism, on the other hand, is concerned with the production and maintenance of ableness; the fallacy of the ‘competent, able body’ as the ultimate goal. One of the central tenets of ableism is the insinuation that there is a hierarchical distinction between non-disabled people and disabled people, and the enforcement of this binary distinction is necessary and beneficial. Another is the view that disability is inherently negative, and all opportunities should be taken to cure, rectify or at the very least ameliorate its effects by any means possible. It is my feeling that there needs to be more work conducted on the workings and understandings of ableism and disablism in order to generate a clearer understanding of both terms and their implied usage.

As has been discussed earlier, one of the ways forward for critical disability studies is to shift the focus of the debate to interrogate the values and principles woven so tightly into the fabric of what is considered ‘ableness’, how this is employed, and the different ways this is maintained. I will now set myself the task of a brief explanation of this phenomena.

2.2c The scourge of Ableism

As I have alluded to earlier in this chapter, the perpetuation of disablism continues, almost unnoticed, through the valuing and naturalisation of the mythical idealisation of the ‘norm’ – in body and mind; the insatiable desire to create an ever more perfected notion of embodiment. If this situation is allowed to continue unheeded, without interrogation of *what* we are injuring ourselves (in many ways) to achieve, and *why* we’re trying to achieve it, the result may prove

to be extremely damaging for all, whichever body one happens to possess. As society changes, the ideal of what is considered able, successful, beautiful, intelligent, productive, achievement, willing and valuable changes too. For example, the invention of smart phones and tablets mean that now workers have no excuse not to be effectively at work, or at the very least on call, *all the time*.

The valued neoliberal citizen, Goodley states, is ‘worn out by the process of life-building’ – the affective coupling of what society hegemonically tells you that you can achieve with capitalist and ableist ideals of perfected embodiment. Goodley aptly puts it, ‘We are quite literally working ourselves to wreck and ruin – under the fantasy that labour will save us and allow us to be recognised – under the inequities of capitalism....’ (Goodley, 2014:65).

Perhaps the cruellest incantation of ableism (and what is to be the focus of my work) is where disabled people internalise the negative valuations of themselves, a topic that has been theorised fantastically by Campbell (2003; 2008; 2009 etc.). It is not my intention here to reproduce ideas already expressed much more eloquently than I could in this short introduction, however I feel that this is an important indication of the slippery quality of ableism, that it has pervaded so deeply into our very souls that even the key players in disability activism were keen to stress that disabled people can achieve exactly the same levels of productivity (with the necessary accommodations) and contribute to the economic foundations of society that they failed to question the ableist undertones lurking beneath these evaluations of selfhood. This is one of the many reasons why the critical study of ableism is so fundamentally important, particularly at a time where the advancements in technology and medicine require a dramatic reevaluation of what it means to be human.

2.2d Is it possible to step outside of the logics of ableism? For example, how do you celebrate success without reproducing ableism?

For me, this is where the blurring of ableism and disablism come into sharp focus. It is the defining of *not* success as undesirable and unwanted conditions, rather than ‘success’ being defined as a gradation of activity. For example, someone who really struggles with maths receiving a C grade would be regarded with pleasure; whereas someone who has habitually found maths easy, and wants to pursue a career in that area may find a C grade disheartening. The grade is relative, rendering it a little meaningless. It is the denigration of *not* success that is problematic for me. It is because everything is relative that objectivity in measuring things like achievement do not work. It also depends on the definition of success that is being

discussed. Is it personal success, or success in the eyes of society? These can be profoundly different phenomena.

Where the critical study of ableism is interesting – and a particularly insightful and thought-provoking activity – is when it forces us to ask questions about the tacit, taken-for-granted rules governing society. It is about questioning the very definition of ‘success’. It is when success becomes acquainted with, and indistinguishable from, *productivity* that the problem with celebrating success comes to the fore. When success is measured on a scale of how productive one is, and what that version of ‘success’ can contribute to society, the whole concept of success becomes warped with societal expectations and obligations. It is the coupling of the neoliberal sentiments of efficiency and productivity that engulf conventional notions of success that signify success as an ableist concept.

If we are able to disentangle ourselves from the strangulating ideals that govern the way that society is structured, then it is entirely possible to celebrate success without reproducing the logics of ableism. It will perhaps take time for us to become disentangled from the competitiveness of ableist relations (arguably brought about through dysconscious engagement with neoliberal values), but I believe that it can be done. We need to dismantle the ideologies that understand and value life based on one’s capacity for productivity and efficiency. By questioning the values incorporated into one’s belief systems, we can learn to define things like ‘success’ on our own terms and in a meaningful way.

2.3 Ableism is all around us, and so the feeling grows...

I will be engaging most significantly with Fiona Kumari Campbell’s (2018) influential work around *Studies in Ableism*. I will be using this as a conceptual lens through which to view the relationship between society and the psyche, and to address the consequences of this around three areas of concern: ableism as it presents itself in research methods; ableism as it presents itself in the lives of university students; and ableism as it presents itself in dominant depictions of motherhood.

Ableism is everywhere. It is evident in the prenatal testing that mothers-to-be are subjected to; in the segregation and subsequent devaluing of certain forms of education; and it is deeply embedded in the structure of town planning systems. It is also covertly apparent in human interactions, for example in the ways that it is deemed perfectly permissible to enquire ‘what happened to you then?’ As it is so deeply embedded, the task of interrogating it is a difficult one. *Studies in Ableism* (SiA) according to my understanding of Campbell (2018), applies

binary thinking but in a manner that is original and allows for the interrogation of the privileged position in that binary. It focuses on what the study of disability can tell us about abledment; what the study of deafness can tell us about what it means to be hearing; and the study of intellectual disability can tell us about what it means to be ‘intellectually able’, even clever. As such, SiA concerns itself with the study of processes and practices, and the uncritical acceptance of these, that maintain the precarious notion of ability. I will proceed to inform the reader of the areas wherein I will specifically be using SiA as a conceptual tool, although this school of thought will form a bedrock for this programme of research as a whole.

Chapter Four will explore an overlooked instance of ableism as it appears in the research encounter, privileging certain modes of communication. I will explore the primacy of vocal interaction as it is used in research contexts, and probe the ableism that the unquestioned supremacy of this contains. I implicate myself as the unintentional purveyor of ableist values in my use of the written word, and promote the search for creativity to be used in research design. I will endeavour to apply a SiA lens to the analysis for Project One, interrogating the psycho-emotional consequences of neoliberal ableist education, and to expose the plethora of ways in which ableism is inextricably bound within neoliberal systems, each toxic component nurturing and feeding off the other. I will further this insight into the exploration of the values inherent within the hegemonic idealisation of motherhood. Ableism will be used as a conceptual tool to extract the often implicit principles undergirding the idealisation of this role, and contemplate on the extent to which these are ableist.

This chapter has sought to outline ableism as a conceptual tool used in both projects of this programme of research, teamed with the theoretical approaches I outlined in Chapter One. The theoretical orientations that I am using will be interwoven and executed in conjunction with this awareness, highlighting the extent to which this favouritism of abilities (Wolbring, 2010) is so deeply ingrained in our culture that the process of assembling and extracting the acts, on both a macro- and a micro-scale, of the oppressive manifestations of ableism will be a monumental task. I am not, therefore, claiming that this programme of research will serve as an end to these insidious processes. What I am aiming to do is to contribute to the awakening, or consciousness, of some of these practices with contextual reference to my own experiences as a disabled mother and student, using ableism as a conceptual tool along with the army of theoretical approaches to guide me in carving a space in which disabled people can feel at home.

SECTION 2: PROJECT ONE

NEOLIBERAL EDUCATION AND THE UNIVERSITY

CHAPTER THREE: METHODOLOGICAL PROCESSES FOR PROJECT ONE

THE WHAT, THE HOW AND THE WHY

3.1 Overview

This thesis, as stated in the Preface, will be divided into two distinct but related programmes of research. In this chapter, I will focus on the methodological approaches I applied to Project One. I will begin this chapter by outlining the main research questions I wished to address with Project One and sketching out the methodological processes I used to frame this inquiry. My use of online research methods will be introduced, and then explored at length as will my recruitment process for participants. I will end this section with an exploration of the way in which I have analysed these precious and complex narratives, and to relate them to the aims and objectives of the programme of research as a whole.

3.2 Research Questions for Project One

The main research questions I wished to address with this study were:

- How is the neoliberal ableist agenda inculcated into educational institutions?
- How does this impact upon the psycho-emotional well-being of disabled people?
- What alternatives could be conceived of for the future of education that goes beyond the neoliberal agenda?

I do not hope to provide concrete, definitive answers to these questions, but instead to stimulate ideas, possibilities and potentialities that will help students, educators and policy makers to consider and reflect upon the educational practices of the future. This study, then, was an invitation to enter into a continuous-becoming, a never-ending cycle of questioning, reflecting and expanding our knowledge *in relationship* with one-another. By employing a postconventionalist, critical social psychoanalytical methodology to the research the aim was to arouse intervention, disrupt hegemonic processes and encourage discussion. I endeavoured to use a variety of data collection tools in order to provide a more equitable approach to the ‘voices’ that were heard, honoured and included within the study.

Some research around disability issues and ‘on’ disabled people has often been felt to be exploitative, abstracted and insensitive (see Charlton, 1998). My aim in this project was to present an alternative, responsive, fresh mode of research design. I aspired to add this study to

the growing desire within research more generally, to alter the boundaries of traditional qualitative research, shifting perceptions of what is possible or desirable by offering a multitude of data collection scenarios. This had the intention of respecting and responding to the hectic and demanding lifestyles of the modern world by offering online research methods along with my own autoethnographic data. I cannot claim that the techniques I will proceed to outline are revolutionary, radical or even innovative, but these are flexible, responsive methods which I believe are most suited to my research questions, the perceived needs of my research participants and my own role as a researcher. I feel that it would be preposterous to purport to ethically explore the psycho-emotional consequences of what I fear is an inflexible, mono-directional institutional system by using set, rigid data collection methods that are not open to a multitude of methods of connection. By expanding the methods, I aimed to offer each participant the opportunity to choose their own preferred way of relating as I see this as a fundamental ethical consideration. This is perhaps the USP of my research design; by focusing not just on the empirical data that is gathered from my participants, but on the indefinable *in-between* of their words, the dynamics of intra-activity (Larson & Phillips, 2013) and the non-tangible effects of the research process itself on the interactions recorded. This acknowledgement of the interconnections and blurring of boundaries that occurs within any intercommunication will, theoretically, open up new space for exploration.

I acknowledge that I am not the first person to explore disabled people's experiences of education; nor am I the first to provide a critique of neoliberal education. What I believe is innovative in this study is the conceptual framework I am using to explore these questions, combined with a data collection method that is more responsive to the perceived needs and desires of my participants. What this study did was to engage with the interplay of social forces and the psyche, raising questions about how the narrowing of education impacts upon self-constructs and relationships with others.

The area that I wished to focus on was post-compulsory educational experiences, generally universities. The participants were approached through the Critical Disability Studies disability research mailing list, (DISABILITY-RESEARCH@JISCMAIL.AC.UK) briefed about the project's aims and objectives, provided with an extensive information sheet and then asked to participate. The information sheet and the initial email are included for the reader's reference in Appendices 3 and 4 respectively. More detail of the recruitment and sampling of participants will be found towards the end of this chapter. The procedures for accruing participants will be

elucidated towards the end of this section also, as will the dilemmas and decision-making processes that this journey was forcing me to consider.

The design of my research was such that the respondents were able to participate as long as they had access to a computer. The potential drawbacks to this will be discussed, along with other potential negatives to conducting research exclusively online. The conceivable benefits contained within the realm of online research methods will also be explained. The fear I had of expanding the project in this way was not to be under-estimated, particularly as my current typing skills, confidence and knowledge of computer-based practices can best be described as limited. Nevertheless, I feel that this expanded the range of possibilities for my participants, which is equally if not more important than my discomfort and unease.

To give the reader a sense of where this section will take us, it will begin with an account of my choice of qualitative paradigm; this, as described earlier, will guide the choice of method and the techniques and strategies I used to analyse my data. The data that I gathered from this study was in the form of stories, anecdotes and reflexive memories; invitations and glimpses into another's (or an Other's) life world. I will then proceed to outline my use of autoethnography and state my reasons for employing this as a valuable research tool. Following this will be an explanation of the proposed methods that will be interwoven with autoethnography, which are: online research methods in the form of email interviews, and Skype interviews. I also offered more creative means of narrating their stories such as photo or reflexive diaries, but these were not adopted by my participants.

I have employed theoretical analysis to make sense of my data. This is pleasing to my conventional self, as it provides flow within my theoretical and methodological orientations; a 'method' to the potential 'madness' of the tangle of competing ways of knowing; and a framework upon which the roses and blooms of postconventionalism and Studies in Ableism (SiA, Campbell, 2009) can be supported, deepened by the creative use of social psychoanalysis. These blooms can then be allowed (and encouraged) to flourish in weird and wonderful ways.

3.3 Interpretive Paradigm

Contained in Appendix 1 is a report considering the relative merits of quantitative analysis and Appendix 2 is a quantitative report, but I considered this approach to be ill-suited to the aims of *this* project which are to relate a myriad of voices illuminating the psychological and emotional consequences of living in neoliberal ableist societies. I found employing a qualitative approach to be much more appropriate to this cause.

For qualitative researchers, concepts are ingrained in relationships, literature, and dialogue; tacit interactions that we as researchers need to think in critical and unconventional ways to uncover. In some ways, we need to become a stranger in our own worlds; to make the familiar strange, constantly questioning hegemonic practices and ‘making silenced discourses speak,’ (Yanow & Schwartz-Shea, 2006: xx). Taylor & Medina (2013:3) envisage the purpose of interpretive research is ‘to understand the culturally different ‘other’ by learning to ‘stand in their shoes’, ‘look through their eyes’ and ‘feel their pleasure or pain’. This is the process that I seek to achieve. However, careful attention needs to be paid to the danger of conflating the participants’ and the researcher’s experiences, particularly when they are strikingly similar. The researcher will need to be skilled in the processes of reflexivity to limit blurring. In chapter one, I sought to outline my ontology and epistemology in an attempt to make these as explicit as possible as these have a profound effect on my theoretical and methodological preferences. My approach reflects a relativist ontology that,

...rests on a belief in the existence of (potentially) multiple, *intersubjectively* constructed ‘truths’ about social, political, cultural and other human events; and on the belief that these understandings can only be accessed, or co-generated, through interactions between researcher and researched as they seek to interpret those events and make those interpretations legible to each other.

(Schwartz-Shea & Yanow, 2012:4)

This dense excerpt needs unpacking, as it contains a number of vital elements for the ‘doing’ of interpretive research. The first being the belief that the ‘truths’ each one of us perceives on the nature of the world around us is intersubjectively created; in other words, our versions of our world depend to a great extent on the ideas, beliefs and reactions that we have absorbed from those around us. More than this, our ontology is affected by the interactions we have with others and the ideologies of society. The pertinent issue here is of how different individuals and institutions respond to the very idea of disability. Through negative portrayals of disability, representation of disability as ‘lack’ and scant representation of positive disabled role models, the messages disabled people may absorb, consciously and unconsciously, about their inherent worth may impact intensely upon their self-esteem (Liddiard, 2013). Secondly, the authors here identify the central importance of the relationship between the researcher and the participants, something which I also feel to have paramount influence on the quality and power of the research encounter. This is an aspect which I will devote deeper attention to. Thirdly, the notion of legibility in relation to analysis of the data, which implies constant clarification and illumination, will also be given added consideration.

To summarise, what I would like the reader to carry with them from this brief introduction to my paradigmatic approach is that I have sought to incorporate an interpretive way of working that honours the written text in terms of reporting and to strive to extrapolate the meaning-making undergirding this text. The intention was to work with differing ways of relating, incorporating written as well as spoken methods of narrating experiences so as to correspond more closely with the participant's preferences. I endeavoured to employ a narrative paradigm that honoured a myriad of voices, both the ones that were explicitly spoken and the ones that were hushed and held back; and one that was analysed using a blend of postconventional ideas that I referred to in Chapter One. Briefly, I employed:

- Autoethnography
- Email interviews
- Skype/video conferencing interviews

I will outline the methods that were embraced in the following sections.

3.4 Research Methods

3.4a Autoethnography as a Research Method

Through telling our stories, we make ourselves. We validate our new identities. We give meaning to our suffering. Our stories shape and structure our experiences rather than simply presenting them to a reader. They tell others who we are, but they also tell us. And more than this, they can make us who we are.

(Richards, 2008:1722)

I have used an element of autoethnographical material in the data corpus for Project One as I am a disabled university student, and the issues inevitably touched on my own experiences. Writing oneself into the field of study can be almost an act of validation. I feel *compelled* to do this; I cannot write about disability as an outsider, pretending that my relationship with/in it is not profoundly entangled and twisted with my experience of my life. 'Disability' and my 'life story' are inextricably intertwined, with more complex intricacies than the traditional disability autobiographies ('triumph over adversity', the 'road to wellness', '*overcoming*' ones impairment etc.) seem to imply. The last two sentences from this quote from Richards here especially resonate with me. This 'telling' did not start and will not end with the completion of the PhD; it is an on-going process. It is in *the telling of the stories* that both the reader and myself will come to know me as an object of the research and as the subject. This self will be elusive and slippery, evading definition as we all are. I want to embrace this *becomingness*. In

the telling of the story, I will have subtly but importantly changed the trajectory of my life. In this way, autoethnography can be extremely powerful. This research method allows me to give an ‘insider’ perspective to my research questions, providing valuable insight that may not be available from other sources. I will revisit this method as I will be making more use of this way of working in Project Two.

Engaging with Online Research Methods

In terms of data quality, a narrator’s fluency and talent in a particular mode of communication will affect what is presented.... As researchers we must continuously ask: who gets to speak and how? To what extent are we limiting this interaction to match our own abilities as researchers?

(Sunderland et al., 2014:7)

This is the sentiment that I am bearing in mind throughout my engagement with the research design. I personally am much more comfortable expressing myself through writing, but am aware that this mode of communication is limiting and restrictive for some. Therefore I wish to offer participants *spoken* forms of representation as well as written narratives in the form of email interviews.

‘Giving a voice’ means more than providing the researched with an opportunity to speak: it involves creating the appropriate means and communication context for the [individual] research participant’ (Seymour, 2001:159). In the context of my research aims, it is also about creating an opportunity for disabled people to contribute to a new way of envisioning education. It is these ‘means’ and ‘contexts’ that I hope to provide, as shall be detailed in the following sections.

3.4b Online interviewing: the use of email to facilitate expression

Feminist theorists have long recognised the psycho-emotional and political significance of reformulating and reframing experiences in a person’s own words, wresting them back from, for example, the patriarchal forces of medicine, challenging normative conceptualisations of ‘victimhood’ and biomedical reductionism (Beard et al., 2009). These stories ‘reverse the dehumanising process of clinical medicine and resist the objectifying surveillance of the medical gaze’ (Garden, 2010:73). By reclaiming agency and providing counter-stories, the idea is to *enable* the participants as far as possible. As I noted earlier, narratives can provide a rich, intimate source of knowledge not only about human lives, but the social practices that are intricately threaded through them. Narratives told through an asynchronous method like email have the benefit of interlocutors being able to respond in their own time, allowing space for

thought and reflection. I often feel rushed and harried with spoken or synchronous methods of communicating, and feel something akin to hatred for parts of my body that are ‘too slow’ to respond with the speed and accuracy that I feel is required of me. This encourages the Cartesian split of mind and body which can be a dangerous preoccupation. Methods of data collection where participants can take their own time to respond may help to alleviate this possible discomfort.

However, the flexibility afforded to the participants may leave the researcher feeling anxious over their respondents’ *actual* participation – if they do pursue the research at all. This invitation to respond as and when participants like must be incorporated into the design of the research (Seymour, 2001), and some boundaries/deadlines should be set to ensure all data is gathered for analysis. I proposed setting an eight-month deadline to give me sufficient time to analyse the data. This, for reasons that will become clear to the reader in Project Two, was not reached but the vast majority of the data was completed by this deadline.

A significant benefit of email and other written forms of data is that this eliminates the cost and effort of transcription, making it an efficient and cost-effective method. Due to my slow typing speed, I would be forced to contract another person to transcribe on my behalf, thus bringing into question notions of confidentiality. The transcription service I employed would also be bound by the ethical boundaries of Sheffield University, but data in a written format would remove this potential complication.

Additionally, being able to respond in this format diminishes any negative ‘interviewer effects’ – indicators around the bodily presence of an interviewer that may make the participant feel uncomfortable such as age or gender (James, 2007). Indeed, as Seymour (2001:158) perceptively notes, when a participant is confronted with an email interview,

...the person responds directly to the [interview questions] and its embedded ambiguities: the meaning is not ‘clarified’ by the researcher; the data are not ‘coaxed’ out of a respondent; and the questions are not rephrased or reformed to elicit a particular response.

This highlights one of the drawbacks of email/online interviewing: the possibility of misinterpretation of the questions. However, this ‘misinterpretation’ could well lead to alternative avenues of exploration.

The disembodied nature of online interviewing may make some people feel more inclined to disclose more sensitive and reflexive material. Indeed, as Bowker & Tuffin (2004:231) assert;

‘Reduced visual cues diminish the possibility of evaluation by others (Matheson & Zanna, 1990). This leads to feelings of disinhibition, affording users greater freedom to express themselves without fear of judgment’. This sense of freedom generated by the lack of bodily presence of another has the potential to yield a more genuine, ‘authentic’ response, particularly when an empathic and conscientious readership is promoted and ensured. The information sheet and consent forms had to be carefully constructed, therefore, to advocate a sense of openness, positive regard and acceptance of whatever experiences they choose to share.

The disembodied nature of online interaction may help too with participants whose first language is not English, as they have increased opportunity to select the right word or phrase compared to face-to-face, synchronous interviews (Seymour, 2001). I wonder if the *disembodiment* implied in online interviewing is an issue worth serious contemplation; does the ‘out of body’ experience in virtual ethnography allow us the space and distance to reflect on our ‘lived’ bodies? I propose that the existence of an *online* persona, distinct and yet entwined with our *bodily* presence, opens up fascinating avenues for exploration.

I am ashamed to admit that there is one obvious major drawback to employing online interviewing that I haven’t yet acknowledged: some disabled people are excluded from this practice. Whilst I endeavour to employ a range of ways of relating, my exclusive focus on computer-generated techniques is engaging in the kinds of dysconscious ableist practices that this programme of research aims to reject. The realisation of this caused me much angst. I feebly justify this through the assertion that these methods are the most comfortable for me, and as the sole researcher I need to take that into account.

CAUTION: What does the notion of ‘disembodied research’ do to our sense of what research is? (A response to Wendy Seymour (2001))

Allow me to take a moment, dear reader, to pause and critically reflect on my dysconscious usage of the term ‘disembodied research’.

Separating the body through increased engagement with online research methods could be a potential site of opportunity for disabled researchers, broadening the techniques with which to engage with diverse ways of relating. Speaking personally, employing online techniques allows me to compartmentalise my research; to bracket off the parts of my body that cause me to feel that I am unequal in this research endeavour. In justifying my use of these techniques, I reflect my shyness, my cautiousness and my need to replicate the qualities I have absorbed around being a ‘good’ student. I felt I needed to protect myself against the potential onslaught of

negative reactions to my disabled speech. It is probably true to infer that the lack of bodily presence of another may help respondents to give more honest and genuine answers. Computer-mediated interaction may also allow disabled researchers to conduct research on a more equal footing.

As I'm writing this, I can see the ableism glaring within these sentiments like a radar alert. The notion of 'disembodied' research seems to infer that to be successful in research, the disabled researcher needs to hide their bodily 'limitations' by cutting out the presence of their actual body in the research encounter. It reifies compulsory ablebodiedness, and signals that to be effective, one must normalise or seek at the very least to approximate normality. It brings to mind the concept of the 'able-disabled' – disabled people who fit within the boundaries of neoliberal citizenship and are therefore conditionally accepted within society's narrow parameters.

Additionally, the term 'disembodied research' implies that it is possible to abstract oneself from the process of the research, as if one's bodymind and one's experience of it do not have any bearing on one's positionality. On the contrary, as I endeavoured to explain in Chapter One, a researcher's positionality is a key factor in determining the story of the research. For disabled researchers, the notion of 'disembodied research' is an even more pertinent one. It implies that there is something lacking in disabled bodies; something that is missing and needs to be masked over.

The internet and online interaction does provide a chance for disabled researchers to, for example, bend time to suit their needs. But it does nothing to actually Crip the research production process as a whole: to make us realise that this is what *needs* to be done; that there needs to be more responsive engagement with alternative methods of data collection; and that conforming to the status quo isn't always what is advisable.

The body is integral to the methods of research production. Normative research relies on standardised concepts of vision, voice, language, cognitive function and so on. The body, rather than being a passive entity, dictates the extent to which researchers are able to comply with the restrictive modes of research production. We need the creativity and the input of disabled people's know-how in order to enliven and expand our capacities for the actual doing of research.

The fact that the modes of research production are tired and outdated is not entirely the fault of non-disabled people. As researchers we all need to push for new ways of doing things, and that includes developing alternative methods for gathering data that are more accessible. Research is meant to generate new ideas, put forth new ways of doing things. We will continue this conversation in Chapter Four, but for now we will re-join our discussion of the methods employed for Project One.

The Use of Email as a Research Tool: Practicalities

The primary purpose of Project One is to identify concerns and obstacles to education in neoliberal societies, and to offer suggestions and alternatives to these competitive, market-driven institutions from the perspective of disabled people themselves. It is a widely held contention that people are dis-abled through an astonishing lack of awareness and consideration of diversity, and the ‘compulsory able-bodiedness’ (McRuer, 2006) that accompany this attitude. In this study, I wish to hold out and inspect the values and ideology undergirding the strength and proliferation of the normative ontology surrounding contemporary education in Western societies. Specifically, I wish to understand how disabled people from a wide range of countries and cultures interpret terms such as ‘able’, ‘ability’, ‘success’, and ‘productiveness’. I also wish to contemplate the effect that an education system that is implicitly based around the idea of disability-as-defective has on the self-worth and self-esteem of disabled people, and I wanted the participants to be able to express their story *on their own terms and in their own way*.

Although I wanted all of the interviews to be open-ended enough to encourage reflection, there was a direction that I wanted the interview to take, and research objectives that needed to be explored. Therefore I aimed to ask around the following interview questions:

- Can you tell me, in as much detail as you’d like, why you wanted to participate in this project?
- Tell me about your life in general. (For example where do you live? Do you like it there? etc.)
- How do you feel others have responded to your disability?
- What do you think are the goals or aims of education? What should they be?
- What is ‘ability’ in your eyes?
- What does the term ‘success’ mean to you?

- In what ways do your definitions of these terms differ from those of your place of education?
- What are the pressures brought about by the focus on achieving ‘academic success’ for individual learners?
- Would you choose to define ‘academic success’ differently, and if so, how? What do you think would be the results of this?
- How do you think academic achievement should be measured, if at all?
- Do you think there should be some ‘key’ subjects to master? Why? What could be the consequences of this?
- Do you think that your teachers’ reaction to your disability helped or hindered you? In what way?
- Can you tell me specifically anything that your teachers/lecturers did that helped you?
- Can you tell me specifically anything that your teachers/lecturers did that you felt hindered you?
- How did your educational experiences make you feel?
- If you could make changes to your educational experiences, what changes would you make?
- If you didn’t have a disability, do you think your educational experiences would have been different?

I feel that these questions go some way into addressing the participant’s personal experiences within education, and to begin to relate them to broader structural and institutional relations within society. By applying a postconventional framework to the fray, the aim was to generate alternative pedagogical practices with the needs and desires of disabled people at their heart.

I felt it was important to allow for an exchange of emails to ensure that the questions were comprehended. I began with the same list of questions, and then participants were invited to elucidate on their replies. I shall now proceed to sketch out another of the online interviewing techniques I employed: Skype interviews.

3.4c Skype interviews

Again, I deem it crucial to construct a research design that incorporates a multitude of communication styles, not just written prose. For too long I have felt shut out of the world because of my lack of ability to communicate verbally; the thought of asking or forcing my participants to communicate in a way that presented similar restrictions on their expression is abhorrent to me. Therefore, I offered an option for a verbal relating style: Skype interviews.

This method is a relatively new technique that allows interviews to take place across geographical boundaries and is thus growing in popularity (see for example Deakin & Wakefield, 2014; Lo Iacono et al., 2016).

The reason I did not offer traditional face-to-face interviews is that it would cause me unnecessary anxiety; whoever the interviewee is, I feel that they are judging me based on my competence (or lack of). It is unfortunate that I react in this way to face-to-face interviews as I wished to be more egalitarian in my research design, and offering only online methods has the potential to have some impact on the findings. This limited the potential pool of participants to a) those who have access to a computer, and b) the faculty to use one. This may have left important voices unheard and, effectively, silenced through my choice of methods. It does, however, flag up areas for further exploration for researchers who may have more experience and confidence with face-to-face interviews and more financial resources at their disposal.

Benefits and Drawbacks of Virtual interviewing (Skype)

With the advent of new technology, communication over long distances has become feasible, accessible and relatively smooth, and the improvements promise to increase as technologies become ever more refined. With this comes the emergence of video conferencing (such as Skype), meaning that (virtual)‘face-to-face’ interviews no longer need to be restricted geographically; the Skype interview is open to participants who may be globally dispersed (Deakin & Wakefield, 2013). As Hannah (2012) notes, this has significant ecological benefits, as the need for long-distance travel is eradicated. Skype interviewing is ‘unconstrained by time and place’ (Seymour, 2001:158), provided the participant and researcher both have a sufficiently strong internet connection to ensure the interview is not unnecessarily interrupted. This, of course, represents one of the potential drawbacks to using any online approaches: the availability and robustness of resources, and confidence of the participant in using those resources. This limited the participant pool and led to issues of representativeness; nevertheless these technologies yield significant returns that cannot be underestimated.

Online synchronous interviews – interviews conducted in real-time – allow for greater flexibility, versatility and choice for participants who may have pain or illness, or who find sitting for long periods of time uncomfortable and unsettling. This could be the same for face-to-face interviews, but the prospect of having to ask an interviewer to leave – particularly when they may have travelled long distances to get there – make this more unlikely. With Skype, it is simply a matter of turning off the camera and logging out. Additionally, participants had the

option of cutting the camera and continuing with the audio, if they so wished and for the period of time that suited them. This may aid disclosure of more sensitive topics, as visual cues of the researchers' reaction to their story will be dissolved, at the same time as hearing audio responses of validation and encouragement. The ability to switch back and forth between camera and audio may provide the respondent with an increased level of agency within the interview process. The advantage of being connected via camera, however, has significant benefits, rendering the setting almost akin to the traditional face-to-face encounter. The researcher will be able to pick up on visual cues such as facial expression, although body language may be more difficult to interpret from purely head and shoulder screen shots and more subtle visual cues may be lost (Deakin & Wakefield, 2013). This way of relating also removed potential issues with typing, as programming a keyboard is painful and laborious for some (including myself (Kerschbaum & Price, 2017)).

Another benefit of the Skype encounter is that only the Skype user details of the participant were required, no other personal information was needed, easing potential concerns they may have had with data storage. This did not, however, eradicate the need and subsequent ethical considerations around storage of audio transcriptions, and participants needed to be assured of the secure storage of these (Liamputtong, 2007; Parry & Mauthner, 2004).

Even when both are proficient users of Skype, there is a chance that the technology will fail (Deakin & Wakefield, 2004). Minor disruptions in the connectivity may cause the connection to falter, possibly losing the 'flow' of the conversation. This is a fundamental concern, with no real means to prevent its occurrence. The conversation could continue with audio, or the interview may have to be rescheduled. Neither is a satisfactory solution. This occurred many times during this process, and proved to be a source of great frustration.

Perhaps one of the major disadvantages to Skype interviewing, and all online interviewing, is the diminished opportunity to create rapport and to establish a personal connection that is seen to be evident with in-person interviewing. However, this relationship is not only built upon personal contact; it can also be established through non-verbal expression of thoughts and feelings (Fielding et al., 2008; Prior, 2017).

The Skype questions followed roughly the same pattern as the e-mail interviews. There were opportunities to extend or curtail the interview at the participant's request. A declaration of consent was either issued verbally, or by 'signing' (initialling) the text function on Skype. Again, the participants were assured that they could discontinue the interview at any time.

3.5 Sampling

The participants were recruited from the Critical Disability Studies (CDS) Disability Research mailing list (disability-research@jiscmail.ac.uk) during the academic year of 2015-16. Members of this list are disabled and non-disabled academics, activists, advocates and others. Members are free to enter into interesting and insightful debates around topics such as the 'correct' terminology to refer to disabled people; post upcoming events and conferences; and invite people to participate in research studies. I have been a member of this group since May 2015. The reason I chose this list in particular is that, on LISTSERV, it has the greatest number of subscribers at 1315, and thus the greatest number of possible participants. The other possibility was choosing the mailing list from DIS-FORUM, targeting disabled students and their support staff, but that has marginally fewer subscribers at 1151. Additionally, the former mailing list is specifically designated for research issues, and so subscribers were theoretically more amenable to being part of a research study.

This method of recruitment ensured that my project has a global reach, attracting participants from many different countries including Canada, America, Poland, Eritrea, Ghana and the UK. Although it was relatively small in scale, the international flavour to this study provides a more secure foundation of its applicability across a range of contexts. However, recruiting my participants as disabled people who have access to a computer had the unfortunate consequence that they may not be representative of disabled people nationally or internationally. However, I still believe that this is a worthwhile project, as listening, respecting and valuing just one voice is just as important, just as 'valid', as listening to a thousand people's voices.

Because of the lack of personal interaction, I had to work hard to ensure that the project's aims and objectives 'spoke' to the participants personally, as I felt that by establishing a personal connection and a desire to engage with the intention of the project, the lack of personal acquaintance could be erased somewhat. On the other hand, the anonymity of the internet implied that participants did not feel obliged to contribute out of a sense of duty to me, and perhaps did not feel as anxious about the personal repercussions of disclosing sensitive information.

Addressing this invitation to participate to English-speaking people from across the globe presented a number of challenges, perhaps the most important of which is around culture and the unspoken codes of conduct governing computer-mediated interactions (Grant, 2003; Sedgwick & Spiers, 2009). Additionally, language and terminology can often be misinterpreted

(Peers et al., 2014). For example, it is considered correct terminology in the US and many other parts of the world to refer to disabled people as ‘people with disabilities’, however in the UK this term is deemed problematic as it is commonly held that the environment effectively disables us through lack of provision, awareness and disparaging attitudes (Shakespeare, 2006). The term ‘people with disabilities’ implies to me that the presence of an impairment that renders a person dis-abled is fixed and unquestionable, and is not affected by cultural expectations and standards. Furthermore, by placing the person in front of the impairment, it seems to be insinuating that there is something inherently *wrong* with having parts of one’s body or mind that work differently to other people. It implies that there is something static – and shameful – that disabled people are dragging around with them: PEOPLE ([whispered] with disabilities). The terms ‘ableism’ and ‘disablism’ are also used differently in different parts of the world; there needed to be a very clear discussion around terminology in this respect.

By limiting the participant pool to English-speakers, I am aware that I have effectively curtailed and disallowed the experiences of many to have their voices heard. This may have had the effect of skewing the research, leaving it open to valid criticism from more majority-world contexts. However, it was not personally or financially viable to extend this particular project to speakers of other languages, and this does leave it open to further research for researchers who have a higher level of funding and skills at their disposal. Additionally, by limiting the participants to those who possess or have the use of a computer, I unintentionally geared it towards inhabitants of relatively wealthy countries. This ‘digital divide’ is a real disadvantage of research using exclusively online methods.

3.6 Ethical Considerations

I have sought to make ethical judgements and appraisals throughout my work. This section will be a summary of the ethical considerations I have undertaken.

Each participant was offered a two-page information sheet, detailing what the project was about, its aims and objectives, and their responsibilities if they chose to take part (appendix 3). It contained information about data protection and confidentiality, and gives both mine, my supervisors and the course secretary’s contact details if they had more questions or they wished to raise a complaint. The recruitment email I sent to introduce myself and the project will be included for the reader’s reference in Appendix 4. This project was approved by the University of Sheffield’s Ethics committee (appendix 5).

I tried to include many ways of relating for the participants, not just imposing my preferred style. This is an attempt to place control and agency over whether, and the extent to which, they choose to participate. The participants operated on their own terms and in their own way. The data collection process was of the participant's choice. I asked them their preferred way of relating, and then further conversations occurred through their chosen method. They were given the opportunity to discuss any issues or misconceptions about the project as a whole, terminology etc. and further instructions were given according to their preferred style at that point.

There was potential for psychological harm to the participants in disclosing deep thoughts and feelings to me. The emotional labour involved in participating in the research was, for some, considerable. This perhaps also presented a level of inconvenience to the participants, although the aim is for it to offer an opportunity to enlighten policy makers and practitioners about the effects of a narrow and normalising educational system on the students themselves. Uprooting painful memories and reliving difficult experiences is never easy, but the hope was that the participants would find it therapeutic and cathartic, and will be enabled to see the potential changes that their participation in this project would help to achieve.

The advantage of the written word expressed over an asynchronous device is that it can be deleted before the researcher sees it, ensuring full consent is given with each interaction. I endeavoured to minimise the fear involved in disclosing personal details by ensuring that each collaborator felt comfortable and safe, in the knowledge that what they revealed was anonymised. Great care was taken to ensure that each participant knew that they could withdraw from the research at any time, with no negative consequences to themselves. I maintained light contact with some of the participants for two to three months after the completion of the data gathering process at their request, in order to minimise distress.

The steps taken to ensure informed consent is given was slightly different for each of the proposed methods. For e-mail interviews, I prepared an information sheet for Project One (see appendix 3) which the participants were asked to study carefully, detailing the aims and objectives of the research, and outlining the possible risks. If they agreed to take part in the study, they were then invited to sign a declaration which reaffirms the confidentiality of their data but also explicitly states that the research may be used in presentations and for further study. The participants were asked to 'sign' their consent using their real name, and then the declaration was printed for my records out and stored in a locked file.

With the Skype interviews, the participants were asked to read the same information sheet, detailing the aims and objectives of the research and outlining potential risks, and explaining the use of their data in subsequent research, and then asked to ‘sign’ a declaration of consent sheet. The signed declaration was then also printed out and stored in a locked file.

It is important to me that this was an ethical, conscientious project that would benefit not only disabled people, but society as a whole by encouraging a closer, more critical look at the values and ideals undergirding educational systems. By doing so, we can hope to identify and weed out unhelpful, ableist attitudes. By identifying neoliberalism and ableism as entwined ideologies, we can remind educators and policy makers that *it doesn't have to be this way*.

In brief, the research methods I used for Project One were:

- Autoethnography;
- Email interviews;
- Skype interviews.

3.7 Pen Portraits

Figure 1 illustrates how each participant was interviewed, their age range and where they were from:

CODE	PSEUDONYM	NATIONALITY	AGE RANGE	CONTACT METHOD	COMPLETION DATE
JD1	Abdu	Eritrean	30-40	Skype	17/11/2015
JD2	Shunuli	Chinese/USA	20-30	Skype	15/12/2015
JD3	Kelly	USA	20-30	Email	17/12/2015 -03/04/2016
JD5	Lilly	Iranian	40-50	Face-to-face interview	16/02/2016
JD6	Ava	Korean/USA	30-40	Email	25/11/15
JD8	Ben	British	20-30	Email/art	09/03/16 -16/06/2016
JD10	Charlotte Dawn	British	40-50	Email	16/12/2015
JD11	Christine	British/African	40-50	Skype	22/06/2016
JD12	Djodjo	Ghanaian	40-50	Email	18/12/2015

JD15	Patrice	USA/African	20-30	Email/digital diary/art	15/03/2016 – 17/03/2016
JD16	Clare	British	40-50	Email	22/12/2015
JD18	M	British	20-30	Email	19/04/2017
JD19	Heather	Canadian	50-60	Skype	24/03/2016
JD20	Crazy chorister	British	30-40	Skype	06/04/2016
JD21	Anton	Polish	20-30	Skype	22/06/2016
JD22	Kate	Polish	20-30	Email	11/08/2016

FIGURE 1: PEN PORTRAITS

In this section, I will be providing some key information about each of my participants. In the initial email that I sent out to recruit for participants, it stipulated that I was interested in individuals that have, or are recognised as having a disability. I did however receive some ($n=3$) emails from people who weren't eligible to participate themselves, but knew someone else who was, thus an effect of 'snowballing' occurred.

I have given each of my participants a code, with my initials and a number corresponding to their first contact with me. Some of the participants ($n=6$) dropped out of the study before completing their data set, and that accounts for the missing numbers. One participant, Kate, dropped out before concluding the final few questions but has since (26/04/17) given me permission to use her existing data. There were a total of 22 participants, but only 17 completed their stories. All names used are pseudonyms.

'Drop-outs'

The major disadvantage with on-line recruitment techniques is that occasionally participants that had previously expressed a strong desire to participate 'drop out', or disengage from the project with no way to establish the reason for this withdrawal. Perhaps they felt, on further reflection, that they didn't have the time to commit to the project; or that they were no longer interested in participating. The frustrating aspect of this is that I was not aware of what I could have done differently. One of the participants that I decided not to include provided an abundance of thought-provoking material, and only had a few questions left to complete his dataset, but he was not responding to my emails and so I was forced to err on the side of caution and discount him from the participant cohort.

JD1: Abdu. (Male)

Skype: 78 minutes, (2 sessions on 17/11/15)

Abdu was the first person who wanted to participate in the project as he thought it was a very worthwhile subject and wanted to contribute his thoughts as a blind man. He is from Ethiopia but is presently living in India pursuing further studies and lecturing. He reported that his family instilled in him a great deal of confidence and self-assurance, and expect a lot from him as a first son. English is not his first language.

JD2: Shunuli. (Female)

Skype, 77 minutes, 1 session on 15/12/15

Shunuli is a prolific disability activist living in the United States. She is currently pursuing a post-graduate law degree. Part of her activism stems from her experience as an under-graduate, where she felt that she was discriminated against in a number of ways, which she goes on to elaborate on in her Skype interview. Shunuli was labelled autistic as a teenager, something which her family were desperate to keep secret. She began to develop a politicalised disabled identity, which merges and interrelates with her East Asian identity and her LGBTQ status, living in a middle class, majority white community.

JD3: Kelly (Female)

Skype, 104 minutes on 17/12; email over 7 months

Kelly is also a prolific disability writer and she was very keen to be involved in my project. She has written and had published a number of stories and articles mostly on her experiences of living with cerebral palsy. She has fought to make a life for herself in the United States. Kelly tells of her experience with the transition from Special Education to 'mainstream', and the trials and tribulations thereof.

JD5: Lilly (Female)

Face- to- face interview: 62 minutes on 16/02/16

Lilly is also a very articulate writer on the subject of disability, and did her PhD on the subject. She was involved in a car accident when she was thirteen which resulted in her disability (like me). Her disability is in her hands (also like me). She has a speech impairment (again, like me!)

and she has mobility issues and is registered as blind. She is originally from the Middle East but now lives and works in the UK. I felt a very personal, powerful connection to Lilly, one that could potentially colour my analysis, so it is crucially important that I use reflexivity here. English is not her first language

JD6: Ava (Female)

Email: two sessions on 25/11/15 and 03/03/2018

Ava is writing from the perspective of a 'hard of hearing, heterosexual Korean adoptee who grew up in Alaska' (Ava's words). She is also therefore writing from the intersections of race, nationality and disability.

JD8: Ben. (Male)

Email: over two sessions on 09/03/16 – 16/06/16

Ben is 27, British and discloses that he has recently been diagnosed with 'ADHD combined type'. Throughout his school years Ben was chastised for being 'lazy' and inattentive, and these words affected him in his pursuit of further education. He states that he didn't do well at school and yet he managed to achieve 10 GCSE's grade A- C. He goes on to describe in detail his experiences both in school and university settings.

JD10: Charlotte Dawn. (Female)

Email, over one session on 16/12/15

Charlotte lives in England with her husband and two children and has a very happy home life. She also lives with ADHD which was diagnosed in adulthood. She talks of the uphill battle she encounters when trying to establish her right to medication and of explaining the symptoms of this condition to others who struggle to understand the effect that it has on her life.

JD11: Christine (Female)

Skype, one session, 59 minutes on 22/06/16

Christine has also only recently been diagnosed with a life-altering condition which affects her ability to be in certain spaces. She has a rare form of light-sensitivity to artificial lights used in workplaces, classrooms, libraries and such like. The progressive nature of her condition has meant that she has had to withdraw from her studies because she couldn't tolerate the lights

used in the lecture halls or libraries. Christine is mixed-race and feels strongly about gender and race issues.

JD12: Djodjo (Male)

Email, one session, 18/12/15

Djodjo lives and works in Ghana, West Africa. He is 48 years old and became deaf later in life, although he doesn't say when. Djodjo's responses were the shortest, but his story is very interesting to me from the glimpses I could glean from the answers to my questions. The overall impression I drew from his feedback was that he felt bound by societal and parental expectations, and yearned to fulfil his own ambitions that would be more satisfying and meaningful to him. English is not his first language.

JD15: Patrice (Female)

Email, two sessions 15/03/2016 – 17/03/2016

Patrice is a young woman from the United States. She was diagnosed with dyslexia in her teens. She fortified her response with examples of art that she had made that she felt demonstrated her ability in a different way, but has since removed them from her website. I have subsequently tried to contact Patrice but to no avail.

JD16: Clare (Female)

Email, one session 22/12/2015

Clare's responses were very touching, and it is clear that she put a lot of effort and thought into them. She wrote a narrative that sometimes addressed my questions, and sometimes went in other directions to express what was important to her. Clare is from the UK, divorced with two children, one of which has ADHD. She has dyslexia which she states makes her work harder to develop strategies to manage her difficulties. She has also been diagnosed with breast cancer, and the medication for that has caused damage to her heart, nerves and joints, resulting in her having pain and mobility issues.

JD18: M. (Male)

Email, over three months

M is an undergraduate student in the UK. This is M's second undergraduate degree, as in his third year of his first studies he began to have what he terms 'psychotic experiences', later diagnosed as bipolar. He achieved a First in his earliest degree, and he has now changed career paths somewhat.

JD19: Heather (Female)

Skype, 64 minutes, one session on 24/3/16

Heather chose to tell her story via Skype. Heather is a 59-year-old woman living in Canada. She has completed her PhD and is now employed in a university there. She has cerebral palsy, and is also happily married to a man with CP. She has been in mainstream education since the age of ten and she believes this has had the impact of her trying incredibly hard to achieve academically.

JD20: Crazy Chorister (Female)

Skype, one session on 06/04/16

This participant is from the UK. She is the only one of my participants to have experienced Special Education throughout all of her compulsory education, after which she attended a mainstream college. Crazy Chorister explains that she followed this with mainstream university, but she encountered problems there after experiencing a mini-stroke. She is a 35 year-old woman living at home with her parents in a small village. She reports that she suffers a lot of teasing and name-calling from the local youths whenever she goes out, but she feels able to defend herself. She sometimes walks with a white cane in places that she doesn't know well. She has a neurological difficulty (I'm not sure exactly what) and she has a valve in her head that needs monitoring.

JD21: Anton (Male)

Skype, 58 minutes, two sessions on 06/05/16

Anton is from a large family in Eastern Europe and is one of a twin. He has a very supportive family, but feels that he was under constant pressure from them to be 'successful', especially in his academic career. He feels pressure from his wider community too, being seen as an 'inspiration'. English is not his first language.

JD22: Kate (Female)

Email, over nine months

Kate is a 29 year old woman with cerebral palsy. Kate, like many others in the study, felt that her disabled status meant that she had to work extra hard to prove that her bodily ‘limitations’ do not negatively affect her intellect and her ability to achieve to ableist standards. She set unremittingly high goals for herself and felt extremely wounded if and when she ‘failed’ to meet those criteria.

3.8 Method of Analysis: Thematic Analysis

I wanted to investigate how deeply instilled concepts of ableism are and how they are perpetuated, as I believe that only by rooting them out can we begin to understand and thus change them. What I am interested in is the extent to which these views are inculcated into educational institutions, which then filter down to infect the minds and bodies of our young people; and the effect this has on disabled people’s sense of self-worth.

As Braun and Clarke assert in their 2018 lecture, thematic analysis can best be seen as an umbrella term for qualitative analyses that focus on identifying patterns across a data set. It is a flexible approach that can be used with a range of theoretical orientations, but here I will be following their stated preference: *reflexive* thematic analysis. What this means is that I will be reflecting on the processes I use to infer my analysis of the participants stories, ‘emphasising the active role of the researcher in the knowledge production process’ (Clarke et al., 2019:6) and using my subjectivity as a valid resource. As such, I aimed to critically engage with the meanings, significance and implications of any patterns identified and acknowledged my active role in doing this.

Braun and Clarke’s (2006; 2013; 2018; 2019) version of thematic analysis appealed to me as a flexible, responsive approach that can be applied across my frameworks of critical social psychoanalysis, studies in ableism and postconventionalism. I wish to focus on the issues within neoliberal university education as experienced by my participants psychologically and emotionally, and to take account of the impact of ableism as operating with/in their worlds. I attempted to conduct my analysis not just at a semantic level, but to uncover the latent assumptions and ideologies that underlie the semantic content of the data (Braun & Clarke, 2006:13). Because of the way that I as a researcher am deeply embedded in the research that I conducted; the length of time between data collection and analysis; and my ontological position as a disabled student, I inevitably brought to the analysis certain predetermined theoretical

concepts. The way that this could have impacted on the analysis is that it could have morphed into a deductive rather than an inductive process with me trying to squash the data corpus into fixed conclusions. My analytical lens and my positionality inevitably had an effect on the analysis procedure.

Because of the laborious one-finger typing I can do, it was not feasible to transcribe the voice-based (in-person and Skype) interviews myself, but they were transcribed in an orthographical manner, recording most of the false starts, interruptions, hesitations, murmurs and pauses of the interview. At first I was horrified at this blatant mapping of my (flaw) and I felt an urge to delete all of my stutters and hesitations in my own reported speech. However these fluctuations in the fluency of speech can be hugely insightful and can be indicative of many aspects of the interview encounter. As all my voice-based interviews were audio-recorded, I have the benefit of being able to revisit them at my leisure, armed with the theoretical lens that has come from the completion of the data collection process.

Braun & Clarke (2006) suggest a 6-step framework for the actual ‘doing’ of thematic analysis, but caution researchers that this should not be seen as a linear, unidirectional process. Instead they encourage conscientious researchers to pause, rethink and retrace these stages in order to achieve a rich, intricate analytical account of the research.

The Braun & Clarke (2006) way (adapted from Braun & Clarke, 2012)

Phase 1: Familiarisation

During phase one, the researcher immerses herself in the data, reading and rereading each transcript or piece of data and making notes on the pertinent sections. Making notes and actively reading the transcripts, Braun and Clarke (2012:60), enables the researcher to ‘treat the data as data’ and to think through what might be implied by the words spoken or, indeed, unspoken. We can then start to get a sense of the participant’s world, and of themselves as operating within that world. Braun and Clarke recommend that the researcher reads through the entire data set at least twice in order to obtain a clearer picture of what they are working with before trying to generate codes. They are encouraged to make notes on individual transcripts as well as the whole data set but at this stage the notes will be more like initial observations rather than in-depth analytical interpretations.

Phase 2: Generating initial codes

This stage is where the researcher contextualises and begins to make sense of the interview transcripts in relation to their particular research question. The codes can be derived from a

semantic reading of the transcript and/or a more latent interpretation that attempts to capture the underlying meaning behind participant's utterings. Codes at this stage can be descriptive, eliciting the actual content of the more pertinent data. As the researcher embraces the context of the transcript, allows herself to become enveloped in the threads of the encounter, she can become more highly tuned in interpreting the particular nuances implied by the participant in relation to your research questions. The researcher needs to read through all the data item for one identified code before moving on to the next code, modifying as necessary. Codes will likely deepen and diversify, potentially splitting into separate codes as the codification procedure develops and matures, and so will require constant re-reading and reabsorption to see the richness of the data throughout. Braun & Clarke (2006; 2012; 2013; 2018; 2019) do not specify a saturation point for the number of codes identified, rather they encourage the researcher to generate enough codes to adequately capture the breadth, diversity and the patterns within each data item and across the data set more broadly.

Phase 3: searching for themes

This is where the analysis starts to take shape as the researcher begins to discern patterns amongst the data set. They will look for broad patterns around which a group of codes clusters, identifying a unifying theme for a group of codes. The way the researcher sculpts these codes is individual to the researcher themselves; the themes are not just waiting to be discovered but are instead a product of the ontology of the researcher, the literature and the data itself. This is abhorrent to researchers coming from a more positivistic stance as it will be incredibly difficult to replicate, even with the same researcher as their experience of conducting this study will inevitably have some degree of influence on any further studies carried out. Themes 'reflect and describe a coherent and meaningful pattern in the data' (Braun & Clarke, 2012:63) in relation to a research question. Certain themes may overlap, and the researcher needs to think at this stage about how the themes will fit together to construct a larger picture, or story of the data. It is useful to view themes as part of a jigsaw puzzle, with each theme as discrete conceptual factors but better construed as part of a larger whole.

Phase 4: reviewing the themes

The developing themes need to be reviewed in relation to the coded data and entire data set (Braun & Clarke, 2012). Questions the researcher needs to ask herself around the quality of the theme include: does this theme tell me something important about my data in relation to my research questions? What are the boundaries of the theme (what does it include/exclude)? Is there enough meaningful data to support this theme? Is the theme coherent enough? Once these

questions are considered, Braun & Clarke advise, the researcher will then need to undertake the second stage in the review process: do these themes work in relation to the entire data set? The aim is to produce a set of themes that capture the ‘most important and relevant aspects of the data’ (Braun & Clarke, 2012:64) whilst giving an overall flavour of the research study.

Phase 5: defining and naming themes

When executing this aspect of the analysis procedure, the researcher needs to be able to state what is distinct and precise about each theme, with the boundaries clearly defined. Good thematic analysis will have themes which are related but do not overlap, and have a singular focus which can be summed up in a few sentences. Together the themes should build up a rich, vibrant picture of the research with a clear focus on the particular research questions addressed. However in qualitative research often the themes themselves can be developed into sub-themes to describe overarching patterns in the data that are linked but are performed in various different ways in the participant’s stories.

Each theme can be illustrated with a few choice extracts from the data that adequately represent the uniqueness of that theme. When selecting extracts to quote, Braun & Clarke (2012:67) warn, the extracts do not simply ‘speak for themselves’. Rather, the researcher needs to explain what is interesting about an extract, what analytical argument it helps to describe, and why they have chosen this particular quotation. The researcher also needs to remember to cite extracts from across the data corpus, not just focus on one or two participants who seem to capture a point eloquently and succinctly. This has special relevance to Project 1 as I focus on the valuation of speech and communication, and I need to fight the urge to select only those participants who neatly summarise the analytical claims I am trying to make. All of my participant’s experiences are equally valid, and I want to represent this factor in my analysis and throughout. This may make the reader’s job slightly more difficult as perhaps the participant’s stories are not ‘pithy’ extracts that concisely sum up my explanatory arguments. This in fact shows the ableist nature of thematic analysis as it has been conceived by Braun and Clarke (2006), and indeed by others advocating this approach. The reader of most research studies wants to discover the new dimensions brought about by the addition of the research to the field, and expects the research to be presented in a succinct and eloquent manner. In this way, reported speech is only valued if it is clear, to-the-point, fluid and articulate. I anticipate tension between wanting to create a good account of my research, and being reflective of the ableism contained in social science investigations themselves. This sentiment will be developed further in Chapter Four.

Phase 6: producing the report

Here the researcher needs to pay close attention to the ordering of the themes. If one theme provides an overarching argument for the rest of the analysis, it makes sense to begin with that theme. The others should build on and take shape from this topic, creating a vivid picture of the research story in relation to the particular research questions, and the study should be embedded in a scholarly field. The researcher needs to make her theoretical orientations abundantly clear throughout thematic analysis, as it is often wrongly conceived of as atheoretical (Braun & Clarke, 2018). The assumptions made by the researcher are ontologically informed, and the final report should give appropriate recognition of this fact. In summary, what is needed in reflexive thematic analysis is a clear, detailed account of what the researcher has done and why they have done it – to focus not only on the content of the study but the process by which it was carried out. This should provide sufficient information for the reader to analyse the quality and credibility of the research.

Through this method of analysis I hoped to co-construct stories that explicitly expose the insidious ableism lurking within our educational systems. It began to weave together experiential, personal narratives and the structures and contours of society, accentuating how each shapes the other. By applying a postconventional framework to the analysis, the aim was to generate alternative pedagogical practices with the needs and desires of disabled people at their heart.

3.9 Thematic Analysis Revisited

This section will attempt to provide a reflection of my thought processes as I navigated the data to extrapolate the poignancy and richness of each transcript in an effort to provide procedural transparency.

I began by thoroughly and painstakingly reviewing each data item, be they interview transcripts, email responses or a combination of the two. Two of these were supported by documentary evidence of art. I had some visceral emotional reactions to many of the stories, and some caused me to relate my own personal accounts. I have tried to separate my experiences from those of my participants by creating a separate section to record them, thus shielding somewhat the conflation of the two. However, as a researcher who has a personal relationship with the subject of this study, I could not (and indeed would not want to) completely extrapolate myself from this research. Instead, I locate myself firmly within the nexus of the inquiry as an active researcher sculpting the analysis.

3.9a Time

I collected my first data item in December 2015; it is now (at the time of writing) October 2019. This is a significant length of time, (which is explained by Project 2) and it brings with it benefits and disadvantages. I wrote three sets of detailed notes for each data item: one brief note immediately following the interview to record my instantaneous psycho-emotional reactions to it; one more detailed analysis at the time, and one final analysis in 2019. This inadvertently provides a slightly more rich and considered approach to the analytical process. By taking the (albeit enforced) time to pause and consider the data, I was able to distance myself from my primary personal reaction to it and to question to what extent this had an effect on my interpretation of the raw data. In this light, the re-analysis of the participant's stories over time affords a more contemplative approach to data analysis and can therefore be seen as a positive asset. In the second stage of analysis, I noted some key topics in the data item, which then helped me identify themes for my thematic analysis. This three-fold procedure allowed me to become familiar with each story, so the process of finding common themes occurring across the data set was much smoother. However as these stories are all dealing with often intimate aspects of my participant's lives, the process of separating these themes was the very opposite.

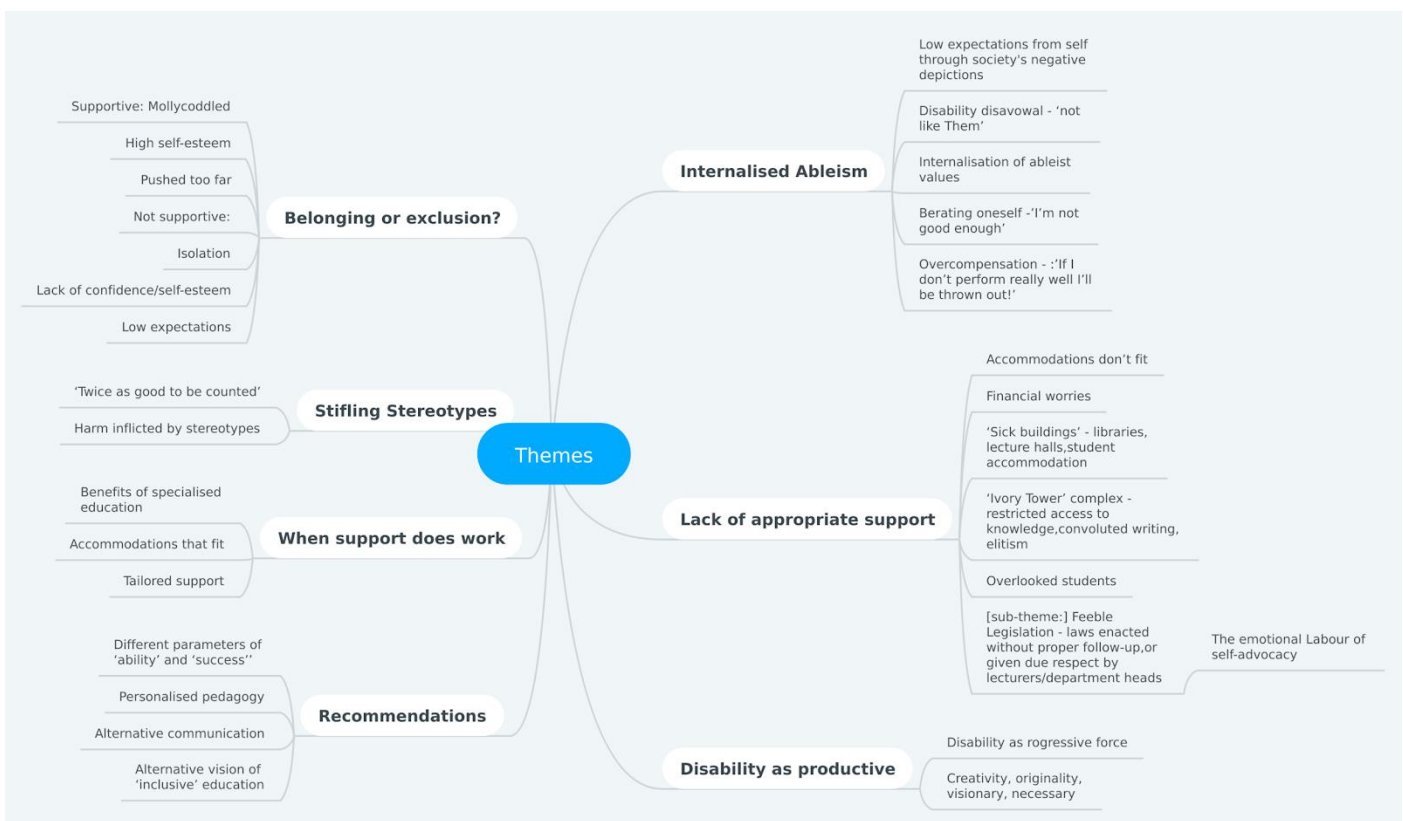
The email responses were a little more difficult to log in this way. For five of the eight respondents who chose email, I had several 'conversations' with each, sometimes over months or even years. I contacted three of the respondents for further information but there was no response. This was particularly unfortunate as one of the participants, Patrice, when I re-read her story it affected me profoundly and I wanted to ensure her wellbeing. Sadly there was no response. This was the main issue with the length of time between data collection and analysis. This meant that my 'imposter syndrome' fears, the insistent feeling that I don't belong in the echelons of academia that have been simmering away since the beginning of my PhD journey, bubbled up to the surface. 'A PhD student', my internal critic chides, 'always puts her PhD first. You need to focus focus focus. What will they (the participants) think? They'll know, they'll find out that you're not worthy of being there, that you can't even do anything properly. Why would they want to continue to provide data? They know its rubbish and you won't do anything worthwhile with it, you're not clever enough!' This negative thinking made me delay reconnecting with my participants, and possibly contributed to the lack of response from them.

However, this stretching of time to incorporate bodily difference granted another constructive element. I was able to immerse myself more deeply in the concept of 'ableism'; to ponder upon

its multifaceted meanings and implications and to think through how it impacts upon disabled students in particular. The extension of time allowed me to do this. I fully support slow scholarship in that it encourages and promotes rich and thorough engagement with the topic of study, and the stretching of time inadvertently encompassed in my PhD journey accurately reflects this.

3.9b The process

I found the prospect of trying to read and make sense of my whole data set in one go terribly daunting, and so I chose the first five transcripts to code initially (JD 1-JD5). As already stated, I already had some idea of how I would order the transcripts thematically from the two of my three-fold analysis procedure. I started by reading my initial notes, and my detailed stage two notes before engaging with the analysis for a third time. I then made extensive notes on each transcript again, and started on the second story. I continued with this process until I had read the first five transcripts before generating possible themes. I examined each story for occurrences of the same theme, adding more as necessary and omitting some that I felt no longer fit. I continued with this process until all of my data set was coded and organised into possible themes. I then refined and developed each theme before generating headings. Again, as I'm reading the data for themes, I am concurrently reading some relevant literature around each theme so I can properly locate my work in the field.



CHAPTER FOUR: ‘SPIT IT OUT’

EXPLORING THE NATURALISATION, NEUTRALISATION AND UNIVERSALISATION OF ABLEISM IN SPEECH

4.1 Overview

The focus of this chapter are the methodological reflections of the techniques I employed in Project One, and to what extent these are ableist. This chapter will hence be a thorough exploration of conventional research methods, and will conclude with the need to develop responsive techniques that are open to multiple ways of relating.

In the last chapter, I described my methods of data collection and my hesitancy with voice-mediated interaction. This ignited a desire – and, what I deem to be a need – to write about the performance of speech and how fluent speech is taken to be an accurate signifier of rationality, and thus the qualification needed to be considered fully human. Most western societies prize performance-related, competitive standards based upon narrow notions of efficiency and productivity. Time is viewed as a commodity - and an inflexible one at that. We are constantly pushed to be proficient and polished, and little accreditation is given to the *process* of becoming. Speech is no different in this respect; it is heralded as an accurate signifier of rationality, reason and integrity. Non-normative voices, then, are relegated at best to a position of inferiority and at worst deemed to be unacceptable and therefore disallowed. By the very act of speaking, according to the values heralded in humanism, we are demonstrating an ability to articulate and form reason. This in turn assumes a position of perfection; it assumes that we all have the capability of speaking in a clear, coherent manner – what St. Pierre (2015) terms ‘the universal speaker’. This privileging of ‘rationality’ and ‘efficiency’ over and above other forms of expression erodes the possibility and virtues of communicating differently.

The notion of speech being universal, open to all, is in itself problematic. As St. Pierre notes (2015:331), ‘As the sine qua non of rational human subjectivity, speech is an esteemed, yet volatile performance that can easily go wrong’. There are many possible reasons for any misinterpretations or perceived errors in speech, and we need to remember that verbal articulation is *not* the only way to communicate. (However, the deliberation of other forms of communication is outside of the realms of this discussion for now). Furthermore, the strength and power that can be gained from withholding speech is not to be underestimated. The way in

which we choose to communicate through speech – or not – can have profound social significance. It is surprising, then, that very little attention (with notable exceptions – St. Pierre, 2012; 2015a, 2015b; Bailey, Harris & Simpson 2015; Eagle 2013; Marshall 2014; Paterson 2012; Richter 2015) has been given to the interconnection of speech/communication studies and critical disability studies. Even in academic critical disability research, it appears to be treated more as a pathology, as evidenced by the overwhelming reliance on spoken presentations to the exclusion of more dynamic ways of showcasing research. The performance of speech contains tacit inference to be accepted as an accurate conveyer of power, authority and self-command, and yet disability studies has so far failed to give this issue the attention it deserves. This piece joins the other recent works that I have listed in fighting for disability studies to enter in to genuine dialogue within the subject of dysfluency. We shall begin this enquiry with an exploration into the naturalisation of vocal discourse.

How do the notions of independence and autonomy feed into and dictate the dominant construction of being a competent speaker? Moreover, why is it that independence and separation are prized over cooperation and mutual connection? Why are these attributes privileged over emotionality and compassion? Methodologically speaking (excuse the pun), how do these processes become enfolded into the research practice, normalising speech between researchers and their participants?

Dysfluent speech brings with it distinct forms of discrimination and punishment, common to other forms of non-apparent disability (Daniels, 2013). Therefore, as St. Pierre (2012; 2015a; 2015b) states, space must be acquired in disability studies to thoroughly engage with this discourse. This chapter will begin my exploration of this subject, starting with a brief explanation of the phenomenological perspective which has been used to a great extent by other authors to frame this enquiry. I will then move into a brief probing of my own psycho-emotional experience of dysfluency, and try to show how this relates to wider society. What will follow will be an outline of the ideology of speech, and an interrogation of the virtues of neoliberalism enslaved intricately within it. Finally, I will use the theoretical musings of other theorists, Joshua St. Pierre in particular, to aid me in questioning the norms that govern verbal interaction, and tentatively broach alternative ways of perceiving speech that represent the interconnection that it entails.

4.2 The contribution of a phenomenological perspective to disability studies

The Social Model of disability has been widely accused (mostly by authors writing from a feminist perspective, e.g. Thomas, (1999), Wendell (1989; 1996), Morris (1992), Crow (1996), Daniels, 2013; 2015) of being divorced from the realities of the body and the effects of impairment. Paterson & Hughes (1999) and St .Pierre (2015b) in particular have attempted to counter this oversight with the addition of a phenomenological perspective to disability studies which ‘posits the body as subject (as well as object)’ (Paterson & Hughes, 1999:598-599). They argue persuasively that a phenomenological perspective would reincorporate the body into a nuanced discourse of disability that would provide a much-needed consideration of the issues surrounding embodied particularity. This would then allow the personal to re-enter political inquiry, reinforcing the connection. It would also begin to withdraw the fabricated separation of body and mind, freeing the body from being trapped by social forces and acknowledging agency. In other words, a phenomenological perspective of disability

...would facilitate the scholarly task of illustrating that the impaired body has a history and is as much a cultural phenomenon as it is a biological entity. It would offer disability studies the opportunity to formulate theories of culture, self and experience, with the body at the centre of its analysis.

(Paterson & Hughes, 1999:600).

Perhaps the most useful contribution of a phenomenological perspective to disability studies is the acknowledgement that it is through our individual bodies and the social forces that we both shape and shape us, that we experience the world. It is the focus on our ‘lived experiences’ that make this perspective a valuable one to the investigation of the meaning of disability. Joshua St. Pierre in particular draws on the concepts of Merleau-Ponty and other writers working from a phenomenological standpoint, incorporating an astute analysis of the way in which our experience of our unique embodiment fuses with a shifting sense of temporality to produce a feeling of being somehow out-of-balance with the hegemonic concept of time. This perspective re-instils the importance of the body as integral to our perception of being-in-the-world, and thus it makes glaringly evident the complexity of being a ‘dysfluent’ speaker. We will explore this in more detail at a later stage in this chapter.

4.3 The ideology of speech

Following St. Pierre, the advent of liberal humanism brought with it a desire for the Cartesian split of the mind and body. According to a critical reading of humanism, the essential proponent of the category ‘human’ is located squarely in the mind ‘merely in possession of a body’

(Hayles, 1999:4; cited in St. Pierre, 2015:332). Coupled with the body, however, this ostensibly rational, autonomous, universal mind falters and fluctuates as it careers along the never-steady process of communication. What, then, of our emotional state and the way that this affects our communicational competence? The way that fatigue hinders our ability to produce sounds at all? The body and the psyche must be drawn into the discourse of communication, but not as an addition or an afterthought, but as an integral part of it. Speech itself occupies an ambiguous position as it relies on the body to externalise the ‘rationality’ captured inside. Assuming that the body is merely a passive vehicle through which the rational mind travels, unobscured, unheeded, denotes that whatever sounds come out of our mouths are a *direct reflection* of our ability to reason, articulate logically and have self-mastery over our actions – thus, in neoliberal ideology, our ability to be recognised as fully human. However, the body interrupts through the production, or not, of the voice. It irrevocably ties the mind to the body. It gets in the way of the supposedly smooth transition of rational mind to outward display of competence and creates a blockage. As St. Pierre (2015:333) recognises, the voice of the stutterer or a person with aphasia, for example, ‘is decidedly *not* at his/her complete disposal’ in the normative way that neoliberalism supposes it to be, ‘precisely because the body obtrudes its continuous emission into the world. The conception of the voice as pure auto-affectation can be maintained only by abstracting speech from lived experience’. The mind – rather than being presented as autonomous and controllable - is exposed, vulnerable to the body’s fallibility.

We are reminded that speech performance is policed by expectations of ‘efficiency, clarity and pace’ (St. Pierre 2012:3), analogous to neoliberal conditions of worth. This creates an expectation of normalised speech – speaking in a way that is quick, to-the-point and systematic. The stutterer, the aphasic, and people with Tourette’s, for example, are then positioned as outsiders, as deficient, lacking and unacceptably chaotic. There is an assumption that, somewhere ‘out there’, there exists a purity against which dysfluent speakers are measured and found wanting. It is through the voice – or lack of it – that our rationality, competence and overall ability are judged. Moreover, emotion and subjectivity are strongly policed within liberal humanist discourse. This policing governs not only *who* is allowed to speak, but also *the way in which* they are allowed to do so; whose speech is validated and respected, and whose speech is discredited and rejected. As such, the next section of this chapter will focus on the emotional valuation of communication.

4.4 The hidden labour and the gendered valuation of speech

Although many studies have focused on the invisible work performed by disabled people (see especially Wilton (2008) and Wong (2000)) – for example, concealing impairments, carrying out informal teaching to work colleagues, acting the ‘super Crip’, acting the indebted beneficiary of other’s support and accommodations etcetera (Liddiard, 2014), comparatively little investigation has been carried out into the *emotional* work of disabled people other than in a workplace setting. The terms ‘emotional work’ and ‘emotional labour’ were initially coined by Arlie Hochschild (1979; 1983) to denote the effort required to suppress, mask or induce feelings and emotional sensations in order to present the required external (and superficial) demeanour to the world. With regard to speech that is considered as dysfluent, managing emotional reactions to the plethora of negative reactions engendered by it can be taxing, as evidenced by my autoethnographical data in this piece. Trying to appear calm and unaffected by the responses to my ‘unusual’ voice inevitably take its toll on my feelings of self-esteem and self-worth.

The emotional work of managing the way in which one presents oneself through social interaction can be arduous, perhaps exacerbated for dysfluent speakers as we *automatically* reveal something about ourselves that we may not want people to know. For example, it makes me acutely uncomfortable that strangers are able to detect my vocal ‘abnormality’ before I can discern whether or not I would want to share my story with them, leading to unwelcome and objectionable questions that often give rise to somewhat disproportionate hostility on my part. This points to the asymmetry (Scully, 2010) of the power differential between non-disabled and disabled people, wherein the majority culture gets to define the norms, pitch and pace of speech. Jackie Leach Scully, in her piece *Hidden Labour*, (2010:35) describes the imbalance of power wherein, within a speech encounter, ‘a disabled individual stands to lose a range of tangible and intangible goods, including respect and self-worth, ...all things that matter deeply to people practically, emotionally and morally’ – and generally speaking, ‘the most that nondisabled people risk is transient embarrassment, loss of face or poise, and the waste of some time’. This perspective underscores that my fear and anxiety surrounding how people will perceive me when I speak allies with and reflects wider criterion that make up the fabric of interconnecting, tacit ‘rules’ governing social life.

However, Scully (2010:35) points to the ‘epistemic advantage’ enjoyed by disabled people at being ‘more sensitised to how and why encounters must be managed’. There is a certain advantage in being on the outside looking in; knowledge that can be gained through observation

of, for example, how fluid speech is valued and why, that may not be elicited with the same nuances from a more etic perspective. According to this view, we as disabled people have unique knowledges that must be protected and hidden if we are to gain anything from the advantage that this knowledge affords us – such as performing a disability in order to have access to support. This can be construed as a kind of manipulation, which can cause significant conflict in feelings and gives an added element of guilt at the deception entailed in social interactions with nondisabled people. The righteous (and, I feel) rightful anger I hold when dealing with hurtful comments (whether they were intended to be or not) about my voice have to be swallowed in order to present a more ‘rational’ persona to the world. This, I feel, is a prime example of a disabled person performing emotional work. Although ostensibly advantageous, as Scully points out, the benefits of insider knowledge only occur because of existing embedded inequalities, such as control over the arbitrary construction of time. Time, as we have seen, is controlled by the dominant (nondisabled) population, and the control over time ‘both indicates and constitutes power’ (St. Pierre, 2015:60).

Revealing emotions in speech is seen to be a sign of weakness and loss of control, and therefore accorded less value. Despite having intricate and entangled connections to the very conditions of existence, emotions and their relevance to social, historical and material life have been somewhat neglected in theoretical study. Furthermore, historically they have been treated as nothing more than *women’s* ‘irrational’ inner sensations and thus relegated to the private sphere. As Williams and Bendelow (1998: xiii) note,

Even to the present day, emotions are seen to be the very antithesis of the scientific mind and its quest for ‘objectivity’, ‘truth’ and ‘wisdom’. Reason rather than emotions is regarded as the ‘indispensable faculty’ for the acquisition of human knowledge.

Regarding research, this view ignores the inherent values and biases that any researcher brings to the table, rendering it effectively invalid. A closer affinity to the study of emotions would facilitate an ontological responsibility to engage in the exploration and validation of alternative ways of being and knowing, as the commitment to ‘rationality’ and ‘objectivity’ has, arguably, contributed to the creation of a world in which the welfare and predicament of others is of little consideration.

Women are generally perceived to be more emotional than men (Hutson-Comeux & Kelly, 2002; Brody & Hall, 2000; Fabes & Martin, 1991), particularly in the outward *expression* of emotions. Indeed, as Hutson-Comeux & Kelly (2002:2) state: ‘Because women are stereotypically seen as ‘emotional,’ their emotional reactions are typically viewed as

overblown and thus are negatively evaluated'. Their study showed that men's emotional reactions were also perceived to be more sincere, more 'real' than women's were. This allies women's voices as being bound to their bodies and emotion, on the other side of the imagined and arbitrary binary of reason and rationality. This in turn effectively denies the embodied particularity of male voices, and is equally damaging to male stereotypes as well as female ones.

'Like other senses, hearing, touch and smell', Hochschild argues, 'emotion is a means by which we continually learn and relearn about a just-now-changed, back-and-forth relation between self and world, the world as it means something just now to the self' (Hochschild, 1998:5). This perspective indicates that, rather than being construed as a separable, distinguishable entity, emotion (or the lack thereof) actually floods through and infiltrates every part of our being, and is intricately tied to culture. Hochschild explores the 'feeling rules' that are tacitly laid down in society that govern how we *should* feel and how we *should* respond to those feelings. In this way, I am often admonished for having (what some would say) an overly hostile response to negative comments about my speech; society's rules dictate that I *should* attempt to act the placid disabled person who accepts that questions must *of course* be asked to satisfy the curiosity of the nondisabled stranger, no matter what kind of feelings that arouses in me. This contributes to a 'splitting' of the social self; knowing the ways in which one *should* react in order to maintain the flow of interaction, but also needing to react to the disablism bound up in these interchanges. This, as I have stated, takes significant emotional labour.

However, we would do well to remember that all oral 'communication is fundamentally unstable' (St. Pierre, 2015:336): it is an act that is fraught with emotion and impulse, imprecision and ambiguity. The 'disabled speaker' is constructed as a necessary antidote to fortify and revitalise the arbitrary construction of the 'universal' speaker. This, I feel, is a salient point. The task of interrogating ableism is to mark and agitate these dominant groups, and to question the naturalisation of their claims. Put another way, critical ableist studies seeks to question the naturalisation of certain human attributes as indicative and essential markers of humanity. Positioning speech as an indicator of the most valid and respected way to communicate, whilst policing it in many restrictive ways, damages and denies other forms of communication. Dysfluent speakers threaten to unmask the tenuous myth that the mind is removed from the body, and to expose the particularity and context that inextricably link the two together. By paying attention to non-normative voices, we are reminded of the precarious and exclusionary nature of the boundaries of the human. As St. Pierre (2015:343) notes,

We must be attuned by/to subaltern voices, receptive to uncertainty, no longer willing to gate keep Reason and human boundaries. Cutting against the tired logocentrism of the universal speaker, impure voices powerfully remind us of the embodied mediation of the human: risky, always partial, ever somewhat wobbly, and necessarily contingent.

4.5 Speech as reciprocal negotiation

St. Pierre goes on to remind us of the dialogical nature of communication, calling for the listener to take some responsibility for any breakdown in communication. Any message received can say as much about the receptor as about the giver, and can be entirely contextual. Miscommunication can therefore be reconfigured as being a signal of as much a ‘lack’ in the hearer as in the speaker. The so-called disabled speaker can be resituated within this network of oral communication to highlight the inherent instability of verbal intercourse, and also serves to accentuate our *inter*-dependence on one another to convey meaning. Indeed,

...by forcing listeners to stretch their ears and linger upon unfamiliar sounds, in denying them ostensibly clear, distinct and terminal signals, the disabled speaker alerts us both to the ubiquitous process of mutually carving out meaning from within noise and to the indeterminate becoming through communication.

(St. Pierre, 2015:346)

In this sentiment, St. Pierre is actively encouraging us to look more closely at the dialogical nature of speech as a communicative interplay between a speaker and a hearer. ‘What if we saw stuttering as constructed by a hearer prejudiced against ‘broken’ speech as well as its speaker, and thus as a product of ableism? Would this allow us to dismantle the myth that stuttering is an individual defect and responsibility?’ (St. Pierre, 2012:6). This nuanced perspective energises and enlivens the phenomenon of communication, opening it up for illuminating exploration. In doing this, we can begin to see the ableist undertones lurking beneath the surface of the norms of conversational delivery; and through this recognition, we can begin to challenge them. St. Pierre begs us to ‘stretch our ears’ (2015:345) in order to properly locate any breakdown in communication as not solely the concern of the speaker, but rather being attributed to the *connection* between the speaker and the hearer when the hearer is ‘heavily conditioned by ‘normal’ hearing (St. Pierre, 2012:7). He implores us to address the construction of normalcy in relation to speech, and to explore the ways in which dominant groups are taken to be natural against which the dysfluent speaker is judged and found to be wanting. The socially created ‘norms’ of speaking and hearing dictate rules that dysfluent speakers continuously disrupt and transgress, and the ‘abled’ hearer is concealed by their

dominant position. Caitlin Marshall, too, argues vociferously on this point, suggesting that speech that we hear as ‘crippled’ is ‘understood through a particular mode of listening and hearing...Crippled speech is thus brought into being by the disabling environment created by normative hearing’ (Marshall, 2014:1-2). Marshall goes further to implicate dominant theories of disability in being oblivious to the material, socio-political and ideological effects that reproduce dysfluent speech as intrinsic biological impairment – effectively denying the ableism inherent within the valuation of ‘normal’ speech.

By assuming hearing to be a passive activity, requiring no effort from the hearer, it is taken for granted that imperfect communication is the fault of the ‘disabled’ speaker alone. This notion is somewhat different within the research encounter, as we shall consider now.

4.6 The spoken word in research contexts

Within the research context, speech – the pauses, hesitations and fluctuations in the speech encounter - are all carefully analysed and assessed. We as researchers listen attentively to each word expressed and reflect on those not expressed, as well as the boundaries and confines that language imposes on us. In this way, the hearer is decidedly *not* passive. I propose that this attentive listening is applied to the hearing act in general in order to recognise and honour the reciprocity of speech action. Qualitative interviews carried out for research purposes through vocal interchange are still the standard. This is profoundly limiting for some, a point which I try to acknowledge in my research design by offering alternative modes of communication. This thesis serves in part to rally the search for an expansion in methods that recognises the complexities of privileging voice-related interaction.

However, there is no escape from the fact that, outside of a research context, voice-related dialogue does follow certain strict, tacit rules and conventions that can often have grim consequences on the self-esteem of those classed as ‘dysfluent’ speakers, bringing to the forefront the observations of a phenomenological perspective.

4.7 The psycho-emotional consequences of being a dysfluent speaker

The medicalisation of dysfluency forces divergent speakers to view their speech as something that is broken, and therefore must be managed. This has potentially profound consequences for the psychological and emotional welfare of dysfluent speakers, and relates intimately with my current research. I still consider it to be a very precious thing, and it gives me incredible relief, when people take sufficient time to listen to me without trying to guess my words (often erroneously, which actually results in the transaction taking longer) and speed up the process

of my attempts at conversation. It is the expectation of rapidity, both from other people and myself, that makes me feel lacking. Discomfort, exacerbated by fatigue, fuels my dysfluency. It takes a great deal of *emotional work* for me to fight against these instances of internalised ableism, and it can often leave me feeling drained and exhausted. I feel like I'm not worthy, of participating in a conversation; of working to this academic level; of even being present. I often feel restricted, not because I cannot express myself verbally, but because I am so conscious of the valuable time I am expecting of others to listen to me adequately and for me to formulate the words that capture what I want to say. This results in me often remaining silent, not participating where I feel I would have valuable contributions to add to a conversation.

Again, I will draw on St. Pierre (2012:12) who sums this perspective up succinctly:

The stutterer finds herself and defines herself in a context dominated by expectations of efficiency. Welded to notions of success and productivity within capitalism, expediency of both labour and communication sets the terms for participation in our socio-economic system while also enforcing the production of the sorts of subject it requires. That is, in light of body politics, the body is *itself* interpreted as that which is meant and required to be efficient and productive... In failing to conform to expectations of efficiency and productivity, the stutterer *herself* is constructed as a faulty instrument that is inefficient and less useful. From this angle, the stutterer feels the pressure of pace from *within*, the pressure to be the sort of efficient subject valued and required for participation. (Italics in original).

However, in *only* interrogating the use of speech and the potential internalised ableism bound within it and I am in grave danger of ignoring the ableism implicit in my own valuing of the ability to communicate in *text*. The potential psycho-emotional harm to participants in judging some forms of written work to be valid and applicable and others not is engaging in the very practices of ableism that I am trying to dismantle.

4.8 The ableism bound in the use of the written word

Sometimes I am so full of feeling, raging with conflicting emotions that I get confused as to how to express myself in the logical, clear way that is expected of me as a budding PhD researcher. Sometimes I actively choose to remain silent in an act of defiance, catching myself almost sneering internally at those who feel the need and compulsion to express themselves verbally. I wonder if this represents a certain ableist attitude in myself. Do I take my ability to express myself through writing for granted? Indeed, as Campbell (2016:5 forthcoming) observes; 'Many people with disability have been deprived of a sufficient education to fully

master the art of literary eloquence. Our impairments can make the device of language impossible to carry memory, meaning and legacy'. Just as before my accident I took the capacity to walk without strict attention to where I was placing my feet, and carrying and lifting things with ease for granted, am I now guilty of taking this same assumption of using text to express myself, and naturalising it as an essential component of being human? What assumptions do I make about people who are not able to express themselves through the written word? I hope that by employing reflexivity and conscientiousness to my work that I will always endeavour not to do that – the length of time it takes me, and the circumstances in which I presently have to write (by myself, in a quiet room with no disturbances) imply that I do actually appreciate the fortuity that my current working practice entails. Perhaps, though, I do need to acknowledge that there is a remnant of ableism, however latent, in my valuing and estimation of the written word. What practices could we collectively use to expand the ways in which we venerate and appreciate the multitude of ways of relating that we all use - consciously, subconsciously or unconsciously – to communicate? This will be a recurring question in my work, and one that I hope to generate a myriad of responses to.

It is my contention that, even if we don't consciously subscribe to external regulations and conform to established ways of being, we are socially engendered to measure and assess ourselves against the 'norm'. It is important to remember, as Kathard (2006:80) points out, that 'When individuals come to understand who they are, or who they should be, they do so against a backdrop of a powerful social value system, i.e. what it means to be 'good' or bad, 'normal' or 'abnormal' in a society'. This can have profound implications for the self-regard of people who communicate differently. Communication – the way we express our very needs and desires – is deeply relevant to our psyche. Language is so important to maintaining relationships; to controlling and negotiating support and information; to understanding and coping with life. This is difficult for many people in a society that puts great emphasis on being able to convey ideas through speech and writing, and often equates these competencies as evidence of intelligence. The body is not a neutral conveyer of information from one person or situation to the next – dysfluent speakers remind us of this fact. Perhaps it is this reminder of the 'fragile mastery' (St. Pierre, 2012:16) we all hold over our bodies that causes the rejection of the 'disabled' speaker.

4.9 The potentialities of dis-fluent speech

Frustrations with communication ‘carry a specific emotional charge’ (Watermeyer & Kathard, 2016:16) as the ability to communicate in a logical, efficient and coherent manner is taken to be one of the essential building blocks for being considered fully human. The ‘human costs of being un-disabled’ (Watermeyer & Kathard, 2016), in this case, an ‘abled’ speaker (St. Pierre, 2012) can bring the psyche into conflict with itself, as pressures to ‘be normal’ agitate and rally against self-acceptance. This discordant understanding of one’s being can lead to exhaustion of the soul; fractures in the essence of the spirit. I find comfort in asking myself, ‘What’s so great about being ‘normal’?’ Normal to me equates with being ordinary, mundane, and insignificant. Why do we strive for this? *Do* we actually strive for it? Studies by St. Pierre (2012; 2015a; 2015b), Goodley (2008; 2011; 2013; 2014), Davis (1995), Titchosky (2001; 2009) and others on the historical, socio-cultural and economic construction of this thing called ‘normalcy’ have helped me to question these standards that I am measured against. Viewing my speech ‘*disfluency*’ in the light of the *social construction* of speech and hearing, instead of the medicalised view of it as signifying an intrinsic inadequacy in my entire being, has helped me to uncover the latent ableism within its conception.

It is my contention that, rather than continue to (consciously or unconsciously) promote the neoliberal sentiments of efficiency, autonomy and productivity through our valuing of normative modes of communication, which inevitably feeds into academic and educational programs, we need to instead focus on *interdependence* and collaboration if we are truly seeking an inclusive system. We need to enlarge and augment the infinite ways in which people choose (or not) to engage with the world.

The communicative structures that dominate our society cut off and outlaw the rhythm and pace of non-normative speakers. The diversification of the communicative field would allow for new modes of relationality to be explored, valued and respected. What would it mean to exist in a time where a slower pace of communication was appreciated and even desired? Where people were allowed and encouraged to dictate their own pace and methods of relating? Where the efforts of understanding and verbalisation were shared activities engaged in with reciprocity and cooperation in mind? This may signal the evolution of a more responsive, more open-minded society.

I have mentioned the notion of time on several occasions in this thesis, as I believe it is integral to a sense of belonging in this world. In this next section, I shall explore how time could be

reconfigured in a way that has the potential to be more inclusive, more flexible, so that it does not solely suit a *particular* type of body and mind.

4.10 The incorporation of ‘Crip time’ to an interrogation of dysfluency

Several scholars working around disability issues have referred to a notion of ‘Crip time’ (see, for example, Michalko, 2010; McRuer, 2014; Kafer 2013; Godden, 2011; Kupperts, 2014; Garland-Thompson, 1997; Titchosky, 2010). This can be taken to refer to academic activities, such as granting more (clock) time to certain students in exams, but also refers to a more abstract, ambiguous sense of time – a time that refuses to conform to the ‘normate’, standard time. Often, Crip time moves at a slower or more erratic pace than ‘culture standard time’ (Michalko, 2010). The time that I need to process auditory information and for my mouth to form the necessary response, for example, could very well fit in to this notion. Goddon (2011:270) makes the comparison with the time of the ‘normate’ and ‘Crip time’, discussing the extra time needed to perform daily activities that nondisabled people take for granted. He reflects, ‘These factors have led me to the impression (sometimes on a purely emotional level) that I do not occupy the same time as my peers... [This leads me to] the feeling of existing in a different, separate temporality from others’. This point of view does not, in my view, signal any necessary hierarchy between ‘culture standard time’ and Crip time; rather, it points out that there is *indeed* a difference. The problems arise when ‘these two time zones are *made* to appear *as if* they co-exist but in one time zone’ (Michalko, 2010:6). This attempted squashing of Crip time into culture standard time can potentially be damaging, and many disabled and nondisabled people alike may flourish if they weren’t forced to live in such a standardised, fast-paced world. Paterson & Hughes (1999:605) argue that it is not just the limitations in structural design that keep disabled people ostracised from participating fully in social life, but the tacit and largely unquestioned norms and pace of ‘communication, timing and proprioception’. I would add to that the norms and pace of understanding and cognitive processing too. This is largely created, Paterson and Hughes suggest, because ‘these norms of duration are exclusively informed by and reflect the carnal needs of people without speech impairment’ (Paterson& Hughes, 1999:606).

We can see something productive in the alternative temporality gained from the incorporation of Crip time. As Kupperts (2014:1) notes; ‘...moments out of time, out of productive, forward-leaning, exciting time, can become moments of disability politics’. Crip time introduces the concept of flexibility and adaptability, insinuating time that is less rigid and obstinate to the needs of every body. As Kafer (2013) explicates:

Crip time is flex time not just expanded but exploded; it requires reimagining our notions of what can and should happen in time, or recognising how expectations of ‘how long things take’ are based on very particular minds and bodies. We can then understand the flexibility of crip time as being not only an accommodation to those who need ‘more time’ but also, and perhaps especially, a challenge to normative and normalizing expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.

(Kafer 2013:27)

Throughout this chapter I have tried to question tacit, taken-for-granted notions such as the valuation of the spoken and the written word as signs of intelligence; the dismissal of emotions in ‘respected’ speech; the pace and efficiency of vocal interchange; and the reciprocity of spoken dialogue. How can we put these considerations into practice in research?

4.11 Putting the ‘Dis’ into Dysfluency: developing a disfluent methodology

Dysfluency is normatively defined in the Miller-Keane Encyclopaedia of Health (n.d.) as: ‘pathology involving speech that exhibits deviations in continuity, fluidity, ease of rate and effort, with hesitations or repetition of sounds, words, or phrases; lack of skilfulness in speech’. This woeful definition often becomes absorbed into the psyches and bodies of disfluent speakers, who ally their speech within this interpretation as signifying lack, incompetence and embodied inconsistency. This can produce low self-esteem, an unwillingness to participate in conversations and overall anxiety. I propose that we reclaim this term, modifying it to *disfluency*.

To ‘dis’ something is to disrupt, unsettle and tear apart the normative register, relentlessly probing and questioning taken-for-granted systems of thought. Disfluent speakers do this automatically – pulling and twisting, bending and expanding sounds and silences, forcing the listener to ‘listen louder’ (Marshall, 2014) and to engage more fully in the reciprocal act of listening. Engaging in the act of disfluent research is to make a commitment to relationality; to focus more on our responsibilities as *actively hearing* components of the research process; and to critically evaluate the values and assumptions undergirding each way of relating. The concept of dis/fluency stimulates and exposes questions of why and how we value fluency. Following Fiona Kumari Campbell (2009) and Dan Goodley (2014), ‘dis-ing’ fluency can open up constructive sites for exploration which can interrogate the concept and the subsequent devaluation of ‘abnormal’ speech. We can become more consciously aware of how dis/fluent speech draws in and complicates the hegemonic expectations of speech and hearing. We can

carefully analyse the expectations around using voice in qualitative interviews to question the normative ableism ingrained in this usage. Applying the concept of dis/fluency to a research setting, we can become more critical about the choices we make in our research designs and the methods we employ to carry out a study. We can become more conscious that, for many people, speech and hearing are value-laden phenomena that represent a multitude of concerns that may trigger internalised ableism. In this recognition, we can become more sensitised, more compassionate to finding and exploring many different ways of communicating that are not limited to the spoken or written word.

In my own PhD journey, I am seeking permission to conduct my assessments in a different manner. Each PhD candidate has to go through an oral examination wherein they defend or speak about the research project they are proposing or defending. This, as the reader may infer from this chapter, aroused feelings of anxiety and dread in me. My supervisor and I worked together to propose a new way of doing this, wherein I would have a list of questions that would be directed at me, and so I had the opportunity to think about them and write my responses, which I would then read out to the assessors. I felt that, in asking for this accommodation, I would be begging and pleading, continuously signifying a 'lack' in me that needed the help of the kindly University. An alternative way of looking at this is that I was challenging the normative and restrictive method of assessment, effectively 'dis-ing' the primacy of speech and voice as the ultimate method of conveying understanding. My research as a whole is, hopefully, disrupting the primacy of normative research. In practice, the concept of dis/fluency results in me feeling more comfortable, more 'at ease' with taking my own Crip time to speak and enter into conversations. I am in effect critiquing the potentially neoliberal underbelly of research, seeking out methodologies that do not result in psycho-emotional ableism. However, I do acknowledge that my use of the written word is potentially exclusionary for some. This is why I have tried to incorporate a range of methods in which participants can communicate their story to me. I am not hoping to provide a universal, 'catch-all' method of research design that would cater for all needs – and would be extremely hesitant to even attempt to do this. What I am attempting to do is explore disfluent methods, keeping the frictions and contradictions in play. I acknowledge that in this exploration, there will be moments of disruption and precarious displacement, but also moments of fluency and continuity where I will be using the written word. There will inevitably be moments of disablism and exclusion, and moments where I draw on dominant modes of research methodology. I hope, though, that this discussion will enliven

and inspire new ways of thinking about research with the notion of dis/fluency an integral consideration.

CHAPTER FIVE: EXPLORING NEOLIBERAL ABLEISM IN THE LIVES OF DISABLED UNIVERSITY STUDENTS

5.1 Overview

This section will reorient the reader to the initial aims of Project One, exploring the psycho-emotional consequences of neoliberal ableist education. I have three key areas of concern that I want to address with this study:

- How is the neoliberal ableist agenda inculcated into university institutions?
- How does this impact upon the psycho-emotional well-being of disabled students?
- What alternatives could be conceived of for the future of education that goes beyond the neoliberal agenda?

This is a project that seeks to uncover the dysconscious (King, 1991; Broderick & Lalvani, 2017) acts of ableism in an educational context, re-cognising and re-presenting them in an effort to unsettle hegemonic practice. Dysconscious processes, as defined by King (1991), are encultured in an ‘uncritical habit of mind (including perceptions, attitudes, assumptions, and beliefs) that justifies inequity and exploitation by accepting the existing order of things as a given’ (King, 1991:135). King originally applied her notion of ‘dysconscious’ to an analysis of racism in teacher education, but I argue that it has particular applicability here. The practices of ableism in education are often characterised not by *unconscious* processes, but by misguided and distorted ways of thinking about disability and disabled students. They are often tacit and unintentional, but this does not justify the harm inflicted onto the students. The biases of neoliberal ableism are so implicit, so ingrained and accepted that disabled students fold these insidious processes on themselves, as we shall discover in the following analysis. This project is conceived of as a way of imagining alternative visions of society that embodiment of disability creatively entails (Mitchell & Snyder, 2015).

I shall be using the theoretical perspectives of Studies in Ableism (SiA) and critical social psychoanalysis especially in this chapter in order to highlight the performance of ableism and the consequences of this performance on my cohort of disabled students. I will touch upon my own experiences of university education, but the voices the reader will hear are predominantly the ones of my participants, interwoven with theoretical literature when appropriate. We shall journey into the depths of the reflexive thematic analysis that I carried out on the data for

Project One, exploring the themes of belonging; lack of appropriate support; and internalised ableism. The second theme, 'lack of appropriate support' is intended to relocate some of the responsibility for the failure of my participants to thrive in their university settings back on to the lack of provision and understanding from the universities themselves. This can have dire consequences on the self-esteem and perceptions of self-worth of my participants, as we shall see. I explore the consequences of compulsory able-bodiedness highlighted by my participant's stories, and reveal the damage that internalising scripts that devalue disability can do.

5.2 Belonging

The interviews conducted provided an abundance of rich data, but it is important that I focus on presenting responses to these key points of concern. The theme of 'belonging' can illuminate important responses to the first two of the research questions especially: how does the neoliberal ableist agenda impact upon the psycho-emotional well-being of disabled students? By focusing on the 'I' voice in the participant's responses, we can glean some significant insights into this central question.

Belonging is a term that academics in the field of social sciences often take for granted (Antonsich, 2010). Belonging is a poignant word, and one that is not commonly associated with literature around disability. It is the antonym, exclusion that is more commonly associated with being or feeling disabled, but the term 'exclusion' has many forms and therefore I feared I may lose the focus of this theme by stretching it to incorporate the gradations of this term. I want to focus more closely here on the sensations of *not* belonging – the disassociation, disconnect, break, the isolation and severance, the longing to be part of something that is not quite within your grasp that my participants recalled in their dialogues. Here I follow Antonsich (2010) in examining the concept of belongingness more closely, extolling a more nuanced conceptualisation of the notion of belonging. Antonsich (2010) recommends separating the emotional, visceral and personal feelings of being 'at home' in a place or situation (what he refers to as 'place-belongingness') and the '*politics* of belonging'; a 'discursive resource that constructs, claims, justifies or resists forms of socio-spatial inclusion/exclusion' (Antonsich, 2010:644). The consideration of both dimensions of this concept provides a socially contextualised analysis of my participant's experiences in this realm. Place-belongingness evokes a sense of comfort, of acceptance. It refers here to a 'symbolic space of familiarity, comfort, safety and emotional attachment' (hooks, 2009:213). Being able to claim it, or not, has a colossal effect on a person's self-esteem (Sanders, 2006). My participant's testimonies lead me to concentrate more on the former of these two conceptualisations of belonging, as this

more appropriately addresses the second research objective. Some of my respondents expressed feelings of comfort and security in their daily lives. However the consequences of feeling excluded – intimately, personally, spatially and intellectually – are explored in relation to my participant’s data. It is not surprising, then, that this was one of the key themes in my participant’s stories.

5.2a High expectations

Kate’s testimony reflects a real sense of emotional attachment and rootedness to her home life. On reading her account, we are provided with a groundedness and feeling of safety that comes from her family’s firm support. She has a strong sense of self-conviction, fostered partly by her family’s belief in her. She states,

I’m very close to my siblings, they all played a huge part in who I am... [My sister] helped care for me when we didn’t live in an adapted home...without her I certainly wouldn’t have achieved as much as I have in my life.

Kate, p1

Kate immediately identifies as disabled, and appears to hold this identity as a significant part of who she is (‘I’m 29 years old with CP, I use a wheelchair 24/7 to mobilise, other dx’s include OCD,GAD, JIA,TRAPS and Keratoconus’). At age two she was diagnosed with severe spastic diplegia, causing her doctors to report to her parents that ‘she wouldn’t amount to much’. However she seems to have internalised the message that she should ‘prove’ her worth, as otherwise she would be letting her family down.

So through determination and sheer hard work and with the help of my family I learnt to write and speak English, Italian and French. I attended mainstream school from the age of 4 and obtained levels of education others around me doubted I’d ever do.

Kate, p5

When I didn’t get high grades I felt like I’d failed anything less to me made it feel pointless... From a young age I measured my success by high grades and if I didn’t achieve these high expectations of myself I would be very upset with myself. I felt being disabled I had to be the best if I didn’t achieve top grades it meant I wasn’t meant to be there.

Kate, p8

Djodjo also protests that he was treated as a ‘superhero’ by some of his peers when first became disabled. Another of my participants, Anton, had similarly high expectations of himself caused in part by his family’s belief that his disability should not be an ‘excuse’ not to achieve. Anton

comes from a small village in Eastern Europe, and he states that the fact that he's doing a PhD means that he's heralded as 'inspiration porn' for others around him. He muses,

My father was quite a driving force in my trying to emulate or surpass the able-bodied people around me...I almost feel compelled to (sighs) live up to those expectations...which ultimately is probably detrimental because it's not a very healthy motivation is it?

This indicates that for some of my participants, family and peer support caused feelings of anxiety and pressure to over-achieve. Heather reveals,

My family didn't fall apart just because their first child had cerebral palsy...My parents just had this expectation that I would do everything that everyone else did... it was quite funny because I don't think my parents ever realised that I had a disability...they didn't articulate my disability as negative.

There was this kind of thing, though, even though it was never articulated by anybody in my family at all, there was this kind of thing that if I didn't perform incredibly well I'd always get sent back to special school.... You have to justify, you have to really over-perform to be seen as a credible person in that respect.

Heather, p12

This attitude suppresses the emotional labour in trying to 'emulate or surpass' able-bodied people in a world that is often ignorant of the needs of disabled students (Bunbury, 2018; Morina, 2016; Goode, 2007; Sanders, 2006). It discounts the extra emotional energy needed to battle everyday disablism (stares, tuts, inappropriate questions etc.) and still endeavour to 'try your best'. Kelly also reported similar feelings of having to perform, often causing her to do 'all-nighters' where she worked tirelessly through the night to ensure that she met the grades that she was expected to achieve in order to stay in mainstream education. Here we can see the effect of compulsory able-bodiedness (McRuer, 2006) on my participants, coupled with the internalisation of neoliberal values. Combined together these can have a profound effect on the emotional, psychological and physical health of a student.

This attitude is noticeable across wider public arenas too. Crazy Chorister mentions her annoyance at the reaction from the public to the Paralympic Games. She states that there is a fallacy amongst the non-disabled that the games

...dramatically improved the perception of disability in the UK – it couldn't be further from the truth.

Crazy chorister, p14

It denotes that prior expectations of disabled people were that we were all inherently inferior, and now we are held up against the talents of disabled athletes and again judged as sub-standard (Kearney et al., 2019). ‘*They can do that, and their impairment is much worse than yours; why can’t you?*’

5.2b Poor prospects

Lilly felt a high level of support from her family, but this translated to her as feeling mollycoddled by them. According to her testimony there was little infrastructure to support disabled adolescents in Iran at the time that she lived there, and she was not encouraged to participate in social activities by her family. This points to a negative effect of being or feeling supported. The lowered expectations of disabled students, coupled with the often over-protective reactions of family and friends, often result in low self-esteem for the disabled student (Sanders, 2006) and a subsequent ‘life time of under achievement and a failure to reach their full potential’ (Sanders, 2006:181). Lilly, as you may recall from her pen portrait, was injured in a car accident at age thirteen, right at the cusp of her adolescence. Being prevented from socialising with friends and developing her sense of self at this monumental time must have been problematic, and potentially affected her sense of belonging in a world that was no longer accessible to her. My own family reacted in a similar way to my disability, wanting to protect me as much as possible and I felt like I had to prove to them that I could be trusted to venture out alone again. I recently applied for my doctor’s notes from the years following the accident, and it said in them, ‘Julia holds unrealistic expectations for the future with regard to resuming her studies; at present she has difficulty dressing herself and she will need psychological support when she realises the extent of her difficulties’. This could be seen as a form of ableist violence (Campbell, 2001), however benign the intentions were. The subject of benign ontological violence is echoed in Abdu’s story. He is the first son in his family, and following Eritrean tradition he is greatly respected and valued by them, and they have high expectations of him. He was brought up with a lot of confidence and felt very much part of the society he was in. He states that up until he attended boarding school he was never aware that his blindness was an issue. Whilst at boarding school Abdu became aware of his blindness as an identity, and formulated strong bonds with others in his school. He is now a lecturer in India, and has had many accomplishments. However, his mother seems to have absorbed the medical imperative to ‘restore’ her son’s eyes:

I mean, I do not know why, I mean I feel like I have done my best with my life and she knows that I am better than her other children and even better than most other people my age...she really understands this but she still wants to restore my eyes.

Abdu, p4

We can see here the conflation of belonging and exclusion, and the imposition of societal values on the feeling of place-belongingness. We can hear the hurt in Abdu's tale, and have a sense of the frustration he must feel at still being seen by his mother as less than perfect. He is torn between wanting to be a good son and respect his mother's wishes, and wanting to rally against this display of ableist behaviour. The politics of belonging, as Antonsich (2010) refers to it, is complex and can have a poignant effect on the psycho-emotional well-being of a person. I do belong (within my supportive network of family/peers), and yet in many important ways I do not. The reminder that society is often blatantly hostile towards disabled people impinges on any place-belongingness my participants felt. The personal, existential sense of being 'at home' is thwarted by society's negative depictions of disabled people.

Crazy Chorister reports experiencing acts of external violence by local youths in her village, where they called her names, imitated the way she walked and threw stones at her. Kelly too felt ostracised at school because of her disability. She says in her email testimony,

The kids in Ms. Russel's class didn't like me, and the only person that spoke to me was Mrs. Allard. She had to. She was the paraprofessional.

Kelly, p1

When I conducted a Skype interview with her to clarify some of the information in her story, she elaborated on this point. She wanted to read what she refers to as a 'cerebral palsy speech' to her classmates in an effort to educate them, but she was prevented from doing so by her teacher on the grounds that it would 'disrupt the class'.

It was only when I was in the sphere of the regular Ed that [my CP] became a negative. It became a stigma. When you've got like thirty kids and they're like noticeably afraid and kids are very honest and they're like physically moving away from you, how else are you going to try to entice them or engage them to be your friend or even just interact with you if you don't explain, you know, 'I have CP, you can't catch it, it's caused by lack of oxygen in the birth canal and from being premature...'

Kelly, p64

The notion of feeling like it is the disabled person's responsibility themselves to educate people about their disability can be seen as an element of emotional work (Hochschild, 1983) and impression management (Goffman, 1963) and can be seen as a consequence of wanting

desperately to belong. The notion that Kelly is a ‘discredited’ person (Goffman, 1963) impedes her sense of belonging to and in a class of reportedly non-disabled others. By reading her speech about the causes of cerebral palsy Kelly is attempting to ‘break through’ (Goffman, 1963:69) – where she is ‘attempt[ing] to move on to a more personal plane where [her] defect will cease to be a crucial factor’. Clearly she wanted to tell the class as a whole not to be afraid of making a personal connection with her. Her teacher should have been the one to do that. Kelly also recounted literally being ousted by her family when she didn’t get funding to pursue her PhD.

It has broken my family apart because I lost my PhD funding, and then I was forced out of my home.... I come from a family of entirely non-disabled, and my twin and older sister were long gone and successful and having jobs and going here there and everywhere and I was stagnant because I was trying to work within the confines of a system that wasn’t set up for me.

Kelly, p20

We can see that Kelly recognises that she is locked into a system that does not cater for her needs, and this, not her CP, is what is impeding her progress towards the life that she wants for herself. This sentiment is reflected in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) preamble:

Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.

Kelly is rejected by her family, was rejected by her peers and, as we will see when we continue with her story, was rejected by her university. The thread of rejection runs sorely through her account.

Patrice reportedly often felt that she didn’t belong at school, due mostly to the failure of her teachers to recognise that she had additional needs that were not being supported. Patrice chose to tell her story via email, and it was littered with spelling and grammatical mistakes that could easily have been diagnosed as dyslexia. Had this been noticed she may have been supported to achieve in the standardised grading system favoured by schools rather than being forced to struggle alone. Reading her story ignites a profound sadness in me, and I get the sense of her feeling forgotten and left behind. She says,

I always felt a shamed of my poor reading, writing, spelling and math skills. Most of my life I struggled in school got bad grades could not figure out why. Nobody tried to

understand me. in school I felt like an outsider it's a scary thing when you can't explain the help you need to people in a place that is suppose to be a resource of learning for a child I just felt nothing but judgement. Not one school staff member ever brought up the subject of dyslexia to the table.

Patrice, p2

Patrice's story is a poignant indicator of how ableist imperatives can do myriad harm to disabled students, shattering their sometimes fragile self-worth with the weight of meaningless obligations. This theme merges with others that I have identified such as lack of resources and internalised ableism, illustrating the precariousness of separating the threads of intricate stories. I feel the theme of belonging encompasses this tale well as it clearly affected her sense of security in the school setting.

Ben also reports that he never felt like he properly 'belonged', calling himself the 'black sheep' (which is an interesting racialized term) of his family. In his email testimony he reveals that he never felt part of social groups; that he was always 'falling out' with his peers and regrets not maintaining long-standing friendships. He attributes this to his late diagnoses as having ADHD. Just after he was diagnosed, he also felt troubled by a sense that was not welcomed into the ADHD clique either;

Suddenly there was an odd ADHD snobbery, and they explained that I didn't have a diagnosis, if I wanted one, I needed to attend the clinic and be diagnosed there. It felt like all my new understanding of myself, my new identity had been ripped out and it felt like I didn't belong. It was very odd to feel rejected by the very people who were acting and being exactly like me, in the room before they questioned my diagnosis I have never felt so comfortable in a room.

Ben, p6

This relates well to the hierarchy of impairment (Deal, 2003; Reeve, 2006) and the phenomenon of disability disavowal which we shall discuss later.

5.2c Other Others

Here we can evoke Antonsich's politics of belonging, and consider how the barometer sways towards exclusion with alarming regularity for students from minority backgrounds (Conron & Wilson, 2019; Meyer, 2003; Pal, 2011). The experiences of other Others (people from ethnic minorities; 'queer' students; and adopted children) will be highlighted in this brief section of the study as three of my participants indicated that their membership of these stigmatised social groups had a significant effect on their feeling of belonging.

Shunuli was ‘transracially and transnationally adopted’ (Shunuli, p31) by white, middle-class, heterosexual American parents. She was raised, along with her (also adopted, Chinese) sister in an area that was predominantly white. Her parents are evangelical Christians and politically conservative. This suggests that she has felt a level of exclusion from a very young age. She is consistently scathing of her privileged background, whilst recognising the advantages that this gave her. She talks about her upbringing in a politicised way, and seems to take strength from her membership of marginalised groups. Shunuli discloses that she had been severely bullied at school by friends and teachers, but she was prevented from leaving by her parents because of the reputation of the school. Additionally, when she was first diagnosed as autistic she was told not ‘to tell anybody about this because it will just be another excuse for them to bully you’. (Shunuli, p38). Prior to diagnosis, the only narratives of disability she had access to were of shame, concealment and restoration.

The only other acceptable way to be disabled is to be somebody's inspo porn...overcomer, overachiever... then you have to hide disability and not talk about it which is not possible because it only increases the shame. Incredibly pathologising.

Shunuli, p38

The reference to ‘inspiration porn’ is a common one in literature surrounding disability issues (see for example Liddiard, 2014; Grue, 2016; and Hadley, 2016). Shunuli experiences the thrust of ontological violence at university through them being consistently resistant to accommodate her needs. She feels like she is being surveyed with suspicion. She states,

... especially someone who is socialised as female, especially as someone who is disabled, as someone who is of colour like I'm constantly doubting my own perceptions because, you know, we're always being told that we're overreacting or we're hypersensitive.. Whereas it's not as bad as you think, it's all in your head, or you're just trying to look for an excuse to be angry...

Shunuli, p23

Shunuli quickly developed a reputation at university as the ‘go-to’ person for disability and legal rights advice, and she appears to draw strength from this position. She talks of regularly organising events and workshops on disability, social justice and inner sexuality. This suggests that, through her experiences of multiple oppression, she has gained an alternative sense of belonging and found comfort in her own way.

Ava is also an adoptee, living in a predominantly white Alaskan town. She identifies as a ‘hard of hearing, heterosexual Korean adoptee’. She appears to have been brought up in a family that appreciates the difficulties of growing up in a hearing world, and she transitioned from

mainstream, to inclusive, to specialised schooling and back again. She states that she is ‘thankful’ (p2) to her parents for encouraging this as she is proficient in ASL, Oral Communication, and Spoken English and this gives her access into both worlds. There is no evidence in her transcript of feeling out of place due to her disability, and this can perhaps be attributed to her being educated, for at least part of her schooling, in an institution that was set up to cater for her individual needs. This may have helped her to feel less singled out. The issue of race was, however, a significant issue for another of my participants, Christine. She states,

In my schooling I had quite, in my early schooling that I went til I was about fourteen I had quite a rough time, erm, suffering with racism and I lived in a small village where it was only like me, my mum and my brother who were the only kind of non-whites, I think there was a Pakistani shopkeeper and that was it, and I suffered with that quite a lot throughout my school.

Christine, p 16

I can relate to her experience, being that I was also bullied up until around age fourteen. I lived in a very white, middle-class area where my mum, auntie, sister and I were the only brown people in the village. The bullying made me feel ashamed, as if there was an essential part of who I was that was unacceptable. Christine continues:

I feel like I have two disabilities, I have my learning disability... but my second disability is I believe is the fact that I am African and that's not a physical disability but that is a social disability, erm, and I my nothing to do to me but disabled me in the education process because I'm within a racist education system, racist sadly, erm that disables my ability to fulfil my potential.

Christine, p33

These interdisciplinary relations of oppression often conspire to create significant dents in the self-esteem of an individual, and throws their sense of security, their place-belongingness in society, into question.

5.2d Dysconscious Ableism

The politics of *not* belonging are powerful, tacit and often unintentional. Able-bodied privilege goes by unnoticed. The harms inflicted upon disabled people are not always consciously intended to do so, but that does not make it any less real for my participants. Certain spaces, and standardised ways of operating in those spaces, can leave disabled students feeling excluded. University buildings are ideologically produced with the dominant able-bodied student in mind. Kitchin (1998:344) articulates: ‘An understanding of how disabled people have become marginalised and excluded within society cannot be understood without an

appreciation of the socio-spatial processes that reproduce social relations'. Kitchin (1998:345) goes on to note how spaces are used to a) keep disabled people 'in their place', and b) to convey that they are 'out of place'. The library is a key site for this. Charlotte laments that, rather than being a place for the sharing of knowledge amongst the community, university libraries and their restricted access means that knowledge is locked within the university and is only accessible to other (socially marked) elites. Additionally, the language that is used to write academic papers has been criticised by Clare and Charlotte as being convoluted 'gobbledegook' (Charlotte, p4). Clare asserts,

I feel that academia should be more accessible to all and should not be wrapped up in complex, convoluted language that excludes many from attempting to understand the nature or outcome of the work.

Clare, p3

Charlotte concurs with this view;

When I left uni after my MA, I was frustrated by the denial of access to the vast amount of research hidden behind the university walls. Unless I find work in a university after my doctorate, I will go back to denial of access. So have I 'succeeded' in the academic sense if I gain the doctorate? Or will I simply go back to being unable to learn what I want to learn again (just as I did during the years and years waiting outside classroom doors) and will the letters after my name have any meaning whatsoever? Will I be disabled by lack of access again, rather than by any impairment I have?

Charlotte, p3

Dolmage (2017) uses the metaphor of the 'steep steps' that often lead to university entrances to signify the ableism in the architecture, designed to keep certain minds and bodies out. In this way, disability is produced by the way we configure space. Dolmage (2017) explains;

The steep steps metaphor describes how the university has been constructed as a place for the very able. The steep steps metaphor puts forward the idea that access to the university is a movement upwards – only the truly 'fit' survive this climb... The self or selves that have been projected upon the space of the university are not just able-bodied and normal, but exceptional, elite. This projection unites many other discourses of normativity: whiteness, heteronormativity, empire, colonialism, masculinity. In connected ways, these discourses push down and mark some bodies whilst insisting on the natural, unmarked place of the privileged at the top of the steps.

(Dolmage, 2017:44-45).

Disabled people are, at best, unintentionally not considered in architectural planning, and at worst wilfully ignored. Indeed,

Good inclusive design will send positive messages to disabled people, messages which tell them, 'you are important', 'we want you here', and 'welcome'... if the way that

disabled people are expected to get into a building is round the back, past the bins and through the kitchens, what does that message communicate? How will it make a disabled person feel?

(Napolitano, 1995:33; cited in Kitchin, 1998:349).

This begs the question, what ideological beliefs *really* underpin university entry? How have universities signalled that I am welcome as a disabled person?

As we shall explore in later, interrelated themes, the lack of appropriate accommodations or initiatives conspire to create feelings of not belonging, of personal incapacity, of failure, of worthlessness. Disabled students succeed in obtaining places in university due in part to the legal requirements of educational institutions, but my participant's stories reveal that ableism is always lurking behind the thin veneer of 'acceptance'. The 'steep steps' of the university are a classic representation of ableism in the extreme, and, as my participant's stories have exposed, often a barrier to belonging.

To belong in a place, Antonsich (2010) reveals, necessitates more than just legal policies designed to protect the needs of oppressed groups. People need to feel valued and listened to if they are to achieve a semblance of belonging. 'The problem', Antonsich (2010:650) observes, is that 'any dominant ethnic group tends to fill the notion of belonging with a rhetoric of sameness, which clearly prevents any recognition of difference'. He goes on to note that, even when a member of the oppressed group has managed to assimilate (or, in Goffman's (1963) terms, 'pass'), there will always remain some dimensions that will prevent the individual from claiming full 'sameness', and 'therefore expose that person to discourses and practices of socio-spatial exclusion' (Antonsich, 2010:650).

By exploring place-belonging and the politics of belonging (Antonsich, 2010) in unison I have hoped to offer a contextualised account of my participant's narratives and to consider how vital this feeling is to human beings as social animals.

5.3 Lack of appropriate support/accommodations

When disability is seen as something 'suffered' by a very few, and otherwise invisible and nonpresent, then disability can never change the culture of higher education, and higher education will continue to wear out students with disabilities, to hold disability itself in abeyance, and to create access fatigue. So, here is a provocative and pessimistic question: What if the college or university is the key space, the key economic mechanism, where disability is delayed, discouraged, and diverted from changing the world?

(Dolmage, 2017:93-94)

Using the UK context as an example (as the majority of my participants were from there or had experience studying there), the issue of ensuring adequate access to education is rather depressing. Despite the Disability Discrimination Act (DDA) in 1995, policies and provisions for disabled students in Britain were not protected legally (Soorenian, 2013). Schools and universities were not legally required to provide accommodations until the Special Educational Needs and Discrimination Act (SENDA) became law in 2001; on the first of September 2002 there was a duty not to treat disabled students less favourably; on the first of September 2003 there was a duty to make adjustments involving auxiliary aids and services; and on the first of September 2005 there was a duty to make adjustments to physical features (Soorenian, 2013:5; SENDA 2003b). In 1990, the advent of the disabled student's allowance (DSA) in Britain allowed disabled students to access Higher Education (HE). This allowance helped disabled students to pay for additional costs because of their disability, such as special equipment, non-medical helpers (such as personal assistants) and travel costs. Under the 2010 to 2015 Conservative and Liberal Democrat coalition government major changes were made to this supportive lifeline for disabled students. Only high-end, high cost computers and other specialised equipment will be paid for where a student needs one solely because of their disability (GOV.UK, disabled students allowance dsa); standard specification computers will no longer be financed. If the course is delivered in a way that the student requires a computer to be able to complete the course effectively, it will no longer be the responsibility of the government to provide for the student in need of support. The student, presumably, will take on the responsibility of trying to ensure that the course is delivered in a way that is appropriate for her to access it. Furthermore, the 'additional costs of specialist accommodation will no longer be met by DSAs, other than in exceptional circumstances' (GOV.UK). It is unclear how 'additional costs' are defined in this respect. These initiatives are designed to reduce reliance on DSA's and encourage greater independence and autonomy for students. In other words, responsibility for ensuring courses are accessible will be transferred onto the students themselves, ensuring a greater burden of emotional labour for disabled students before they even begin their studies.

These 'modernisations' (in the words of the ministerial statement given by David Willets), are fashioned with the aim of 'rebalancing' the level of support offered by higher education institutions (HEI's) and the government. So it will be the responsibility of HEI's to offer their very limited funds to support disabled students. This implies that the range and suitability of support offered will diminish, and, as noted previously, it attributes responsibility onto the

students themselves. As we will explore, the very language surrounding ‘reasonable accommodation’ thinly disguises the approach to ‘allowing’ disabled students to access the exclusionary ‘steep steps’ (Dolmage, 2017) of the ivory tower. Indeed, this is reflected in the paucity of students who identified as disabled entering higher education. According to recent statistics from Oxford University, in 2016 only 13.7% of successful applicants declared a disability in their UCAS applications (ox.ac.uk). 11.9% of successful applicants declaring disability were admitted into the Russell Group of universities in 2016, and 7.2% were admitted into Oxford University (ox.ac.uk). However, out of 930 applicants to Oxford in the same year, only 190 were successful –this is a mere 12.5%. This shows that disabled people, for a multitude of reasons, are less likely to apply for and successfully enter universities (Madriaga, 2007).

Shunuli in particular had many stories to tell around lack of appropriate support and accommodations. As the reader may recall, Shunuli is a disability advocate at her university, and thus reported many woeful tales of disablism, often *institutionalised* disablism. (Note: she often uses the term ableism as I would define *disablism*). She quotes one example,

A certain blind student goes to the disabled student’s office and is like, ‘hi, so basically I go here and I am totally blind, here’s my medical record also saying that I am totally blind...and anyway, can I have my stuff in Braille? And the Disabled Student’s Services office looks at this person like looks directly at this person and says, ‘we don’t have to give you Braille, coming to school is a choice’.

Shunuli, p5

This attitude seems to reflect yet another ableist framing; that that a disability is the responsibility of the student. In this way, the university can deflect the duty of accessing appropriate materials onto the disabled student, thus highlighting their particular ‘deficiencies’. Shunuli goes on to relate the segregation that is metered out to anyone disclosing a physical disability. She explains that everyone with any kind of mobility difficulty is placed in a single dorm on campus, with no regard to the year of study of the student and thus their social needs. She laments, ‘you don’t get a freshman experience’. The freedom to choose here, which is available to all other students, is restricted on the grounds of the presence of impairment. The ignorance with which buildings are constructed is another source of frustration for Shunuli; she shares an account of her experience with a new building on her campus with a particularly heavy set of double doors with no button, effectively restricting access for all but the very strong. Ability privilege is not recognised.

Kelly recounts a similar story around the lack of consideration for wheelchair users affecting her choice of university. She describes the lack of access for students with any kind of mobility difficulty, especially in the winter with heavy snow, and indicates that this was not a consideration of the institution but would be interpreted as the student's own responsibility. She decries,

Really, like how the hell am I supposed to get around the campus cos you've got like huge hills and then, and then like snow and ice... we wanted accessible housing and he [the interviewer] basically said, 'no, that's up to you because we wouldn't help a non-disabled student either...I didn't end up going it was just devastating. In a sense, regular education has ruined my life. They're a combination, either you don't get the academic accommodations which make it impossible for you to continue, or you don't get the accessible housing or some miserable disgusting combination of both.

Kelly, p19

I had numerous difficulties negotiating support when I first became disabled and returned to university nine months after the accident. My DSA was very generous, awarding me with a new state-of-the-art laptop, desk, and voice recorder. I had a note-taker for my lectures as I was unable to write at speed (or write at all at that stage). I thought this was wonderful, and felt very grateful to have been offered these supports. However, the reality of having to work in an entirely new way was not constructive and led to a spiral of self-blame. My notes from the lectures were useless, as the note-taker was not from my discipline and only took bullet-point style notes, where I had previously taken extensive notes, especially on the topic of the essay that I was going to write. My memory for specific details was affected badly, so I was unable to recall precise information. Through the effects of internalised ableism, I was unaware that I could ask for a different note-taker, or for the lecturers to print out their lecture notes for me or for any other more suitable accommodations to be offered. I have always been used to writing a detailed essay plan, giving myself written instructions to guide me when I came to construct my essays. Using a voice recorder to compose my essays was an entirely new experience for me, and one that I found incredibly difficult to grapple with. I suspect that I also have an audio-processing difficulty, so rewinding and listening to the tape to evaluate my work was both counter-intuitive and uncomfortable, as was listening to my new voice after the effects of the vocal surgery (due to the paralysis of my left vocal cord). Due to the length of time each essay would take, I was forced to choose the first essay topic that was covered in the lectures, as the amount of revision that I would have to do to the structure and content of the essay was

substantial. The transcript would invariably come back with typos, grammatical mistakes and a completely nonsensical version of the original verbal recording. The finished product would categorically not be representative of my potential, and my grades reflected that.

5.3a Negotiating access and the pressures of self-advocacy

The burden of advocating for yourself and negotiating workable accommodations is another facet of the education process that the non-disabled are unencumbered with (see Katzman et al., 2020 for a detailed account of the relational work of self-managing attendant services). For me, the prospect of studying to the high level that is required for university after the accident was pressure enough, never mind having to deal with a new version of yourself *and* negotiate the support that you will need. It is akin to being at a restaurant, and the waiter demands to know what you want without you having looked at the menu. I didn't know the range of supports that could have been useful to me.

Many participants reported the emotional labour of having to self-advocate often made them physically sick. Ben informs us,

At times it has made me quite ill, it made me feel stupid, unconfident and useless. It made me question why I couldn't be more like others. I've found the whole experience a slog and I've often referred to it as an endurance test. Without sounding dramatic, it felt like being imprisoned.

Ben, p12

Crazy Chorister also reported difficulties with negotiating support, inferring that this took valuable time and caused undue stress. She describes her third attempt at her Foundation year as 'torturous', (p3) due in part to what she describes as 'personality clashes' (p3) with lecturers and staff. Additionally, she had a mini stroke during her second year and the death of someone close to her. In her opinion, the staff displayed little to no understanding of head injuries and the subsequent effect on mood, and the university failed to respond appropriately to her situation. She finally was paired with a tutor who was a prolific disability writer and activist – but according to Crazy Chorister, was impractical as he had no knowledge of her discipline. These stories show the impact on emotional well-being of negotiating access and support.

Kelly declares that the lack of appropriate support and constantly having to self-advocate,

...literally made me physically sick, and it made me emotionally sick I mean I'm still taking antidepressants because of what happened because I will never be able to forget that chapter of, you know, working for the two years to take the oath and then not to get accommodations...

Kelly, p32

Kelly resents the fact that securing appropriate accommodations was left to her alone, increasing her feelings of loneliness and isolation at university. The reluctance with which she secured any accommodations at all is evidence of the exclusionary forces at play in academia.

It's always been me being the pioneer, it's sort of been my role it's always me negotiating everything on my own and then it goes wrong.

Kelly, p 41

M reflects on the wider implications of striving to 'achieve' to ableist ideals, stating that he 'somewhat sacrificed my health by focusing on 'academic success'' (M, p 10) (Giese & Ruin, 2018); Kearney et al., 2019). Christine identifies the struggle of negotiating accommodations when the disabling effects of a condition are not recognised as a disability, and therefore not afforded the same support that a more recognised visible disability are (Wendell, 2001; Daniels, 2013; Humphrey, 2000; Orlando, 2012; Evans, 2017; Samuels, 2003). She suffers from a form of photophobia, what she refers to as an allergy to light. She experiences constant head pain, confusion, anxiety and 'anger with sound' (Christine, p6). She discloses,

It's difficult to get any real relief, especially in winter, once it goes dark then I kind of start shutting down. It was like losing my mind. I believe my actual disability is made worse by the university environment, harsh artificial lighting in the library which I believe actually ground my brain to a halt after a while...

Christine, p3

The emotional labour (Hochschild, 1983; Liddiard, 2014) of having to fight a battle on two fronts clearly affected Christine, leading to her having to abandon her studies after doing the vast majority of the work, at a significant cost to her health. I have written elsewhere (Daniels, 2013) about the burden of not being believed when one's disability isn't immediately visible to others, and it evidently damaged Christine in this situation.

5.3b Ableist ideals

The insinuation that negotiating support should be the student's responsibility is akin to the medical model: seeking a deficiency located *within the student*, which they then have to mitigate for in order to best approximate the (imagined) norm. This responsibility causes excess emotional labour for the student, a cross which they should not have to bear. Admittedly, this is pursued under the guise of autonomy; the disabled student themselves being able to choose the kind of support they need, and as a result gaining power (Fossey et al., 2017) but, as is evidenced by my participant's narratives, this serves as a further burden to some students.

The standardisation of education was an issue highlighted by many of my participants as effectively blocking access to higher education. For example, Djodjo lamented the restrictive effects of the situation in Ghana, which mirrors the UK. He explains that in Ghana, social studies, maths, English and science are mandatory, and ‘one cannot further one’s education if one’s grade is below the national threshold’ (Djodjo, p2). This means that, even if a student has an exemplary flair for social sciences, for example, she cannot progress further if she fails to pass the threshold grade in Maths.

Kelly narrates her difficulties encountering lecturers that were concerned with getting through the syllabus rather than ensuring understanding. She notes repeatedly asking questions that were ignored, meaning that ‘every day you have less of a foundation, you understand less and less’ (Kelly, p54). This problematizes constructing the curriculum with an ableist ideal in mind. Dolmage (2017:102), drawing on the character invented by the president of Boston University in 1995 Jon Westling, fabricates two characters to represent the extremes imagined by universities; Somnolent Samantha and Super Samantha. These two caricatures are meant to represent the inverse of each other. The ideal that Super Samantha presents, according to Dolmage (2017), is neoliberal ableism in the extreme – she is technologically proficient, flexible, energetic and of superior intelligence, – even to the teachers themselves. She leads educational institutions to create learning opportunities that are fast-paced and innovative enough to keep up with her. She creates fear that if they don’t cater for her every whim, she will leave them behind in a flurry of brilliance on a global scale. However, this caricatured student is a danger to the ‘protections’ offered by accommodations. As evidenced by the startling article by Lerner (2004, described below), accommodations are often heralded as happening at the cost of other students, especially the Super Samantha’s of this world. Dolmage (2017:107) warns,

So long as we are straining to change for the ideal student, and for a new knowledge economy, we can ignore the inequities that may have positioned her ahead of the pack to begin with. We can ignore the economic realities that make Super students temporarily valuable. And we can definitely avoid wasting time on the stragglers.

Heather, who works in academia in Scotland, agrees with this point. She affirms,

I think that there are a lot of individuals in academia that have this underlying belief, and it may not even be a conscious belief, that if disabled people are present in large numbers then somehow the quality of the institution is compromised because we are present.

Heather, p3

Charlotte also notes that some lecturers hold an implicit bias against inclusion. She recalls,

I remember one lecturer telling me that universities could either value inclusion but (and she held her hands out in a see-saw motion) inclusion lowers academic excellence. I think I may have a different definition of 'excellence' as well as 'success' and 'ability' than her.

Charlotte, p3

This reflects the compulsory able-bodiedness and able-mindedness of academia, and the pervasive assumption that universities are the pinnacle of society and thus cannot be 'polluted' by traditionally impure populations.

The latter imaginary student, Somnolent Samantha, 'greedily demands extra time on assignments and exams, copies of notes from lectures, a seat at the front of the class, and a separate room in which to take tests' (Dolmage, 2017:102). My narrative could easily be taken as representative of Somnolent Samantha. Whilst studying for my counselling diploma, I was given a note-taker who would sit alongside me. However, she 'demanded' the use of a table on which to write her notes, disturbing the class layout of the circle. Many of my classmates objected to this, and used to stare at both of us with utter contempt. One of my lecturers on this course would not allow me to prerecord my presentation, saying that this process would be unfair to the other students. I was under the impression that I would meet people with a shred of empathy by pursuing a course such as this; I was sorely disappointed.

These types of students, Dolmage (2017) warns, get invented through the reluctance to provide accommodations in higher education. Whilst researching for this theme, I came across a contemptible paper by Lerner, 2004 entitled, 'Accommodations for the learning disabled: level playing field or affirmative action for elites?' The article implies that American students are increasingly fabricating a learning disability in order to gain accommodations;

Indeed, one should expect people who are not handicapped at all to 'spooft' disabilities in order to obtain favorable legal treatment...Yet psychologists and educators, apparently throwing scientific rigor to the winds, have stamped ever-growing numbers of students learning disabled, therefore qualifying them for legal accommodations.

Lerner, 2004:1047)

In his article, he disputes the fact that 'the learning disabled' are entitled to any protection whatsoever under the Americans with Disabilities Act (ADA) which became law in 1990, citing a number of legal cases where a plaintiff attempted to sue the government with regards

to a definitive physical disability and lost. Lerner comments on the ambiguity of the definitions of disability set out in the ADA: 'The ADA limits the protected class of the disabled to those suffering from 'a physical or mental impairment that substantially limits one or more of the major life activities of an individual.' (Lerner, 2004:1079). The subjectivity of the statements, 'substantially limits' and 'major life activity' are, admittedly, open to interpretation. The rest of this piece openly implies that some discrimination against disabled people is to be considered 'rational' and even to be encouraged in the name of economic profitability. A profit-maximising company, he retorts, would surely be deemed rational for employing an 'able bodied' applicant rather than a deaf one, with her needs for accommodations and interpreters (Lerner, 2004:1053). His paper is littered with such examples of blatant disablism under the guise of 'rationality'. He habitually makes reference to the 'normal' person with 'common sense' attitudes without actually discerning to define what he considers 'normal' to be. He appeals to the 'normal, rational' person's sense of fairness, and proposes that we (an undefined group) all share the same values and sense of justice. My research suggests that this attitude is pervasive in university institutions, albeit veiled. Indeed, when Shunuli disclosed to her lecturer that she has an audio-processing difficulty, and asked for help in another aspect of her Arabic course, the lecturer replied, 'if you have difficulties with that, why bother trying to learn a language at all?' Ryan (2005:47) observes,

Institutional and teacher responses to the needs of higher education students with learning disabilities are generally characterised by an expectation that students need to develop *compensatory strategies* to remediate the effects of their learning deficits in order to achieve academic success. (My emphasis).

Clare prides herself on her ability to 'develop compensatory strategies' and suggests that this is how she has succeeded thus far in education. Kelly described feeling the need to do 'all-nighters' at the age of nine to keep up with the teacher's expectations because, in her opinion, they did not want to follow the stipulations of her Personal Education Plan. 'They agreed to it but then they would mark me with zeros because they personally didn't agree with it but they were made to agree...' (p13). We can see the urge to emulate a non-disabled – and an *ableist* - identity played out in Ava's narrative as she struggled through her mainstream education without an appropriate level of support. In reference to her eventually securing funds from the Disabled Students Allowance (funds given to a student who declares a disability to support their studies in the UK), Charlotte notes the hostile response from her peers;

...Eventually I was given access to some support through Disabled Students Allowance. A 'friend' told me she wished she had a label so she could 'get free stuff too'.

Charlotte, p1

Individual students are pulled out as having individual shortfalls that need to be corrected. The very presence of disabled students in university education serves to uncover normative assumptions of the 'ideal' student through the labelling of what is *not* desirable, and the range of teaching practices that need to be accommodated for (Ryan, 2005; Goodley, 2014). In other words, turning a SiA (Campbell, 2009) lens on the policies and practices of tertiary education reveal the cracks within pedagogical practice; the timeworn methods of teaching that no longer serve their purpose (if they ever did at all) (Rice et al., 2018). It calls our attention to the insinuation that didactic and teleological teaching practices are not useful, effective or applicable to all students. Engaging with the processes of reflexive analysis, for example, may not prove 'productive' in the typical sense, but may be considerably enriching for the particular student. This challenges universities and their teaching staff to create new methods of engaging students that are more relevant to today's society. The reluctance with which 'accommodations' are carried out reveal the inherent disablism still rampant in education, and reflect the view that university education should be only secured for the elite – the financially stable, compliant student who is proficient in the mono-literacy that has been narrowly defined as guaranteeing 'academic success'. Accommodations, according to Dolmage (2017) are not designed for disabled students to thrive, but to make the disability temporarily go away. 'The aspiration', Dolmage articulates, 'is not to empower students with a disability, but to achieve around disability or against it, or in spite of it' (Dolmage, 2017:70).

5.3c Feeble legislation

Laws are only effective if everyone in society adheres to them. They must have some societal backing in order for them to prove useful. With reference to the laws protecting disabled students from discriminating practices, it will need the full support and education of the teaching staff in order for this legislation to be competent in battling disablism. If, as we have seen with Kelly's teacher, there is an underlying view that disabled students should not be afforded the same rights or respect as other students, then these laws will be impotent. Moreover, Kelly proclaimed to me that universities in the United States are afforded additional funding if they are seen to be 'disability friendly', whether they are indeed accessible or not. Kelly reports,

Here you have a public school claiming to be handicap accessible getting millions of dollars from the federal government and they're not but nobody wants to take on the case...

Kelly, p62

Shunuli recounts her success at university at persuading them to open an LGBTQ centre, the first Catholic institution to do so. Shunuli was concerned that this centre be accessible for everyone, and they agreed to put a Braille sign on the door. However, they put the sign *above the door frame*, 'because, didn't you know, every blind person is eight feet tall?' (Shunuli, p6). This is an example of what can happen when there is no real understanding of disability issues, and universities are merely ticking boxes. Shunuli's analogy of the building of the state-of-the-art new science block that I referenced earlier, with the heavy double doors is another example of laws being enacted with little understanding of the people that are supposed to benefit the most from them. Shunuli recounts yet another story of cultural and relational barriers that she dealt with in her position as a disability rights officer whilst at university. A blind student on a linguistics course was in class, and the professor announced that

...you need to be able to see and hear in order to have language and thought....[she was] raising her hand repeatedly and the professor refused to call on her whilst literally saying that blind and deaf people can't think.

Shunuli, p17

Shunuli reports yet another example, this time referring to her own experience. She relates that she was having issues communicating with a certain professor, so she decided to go to his office and talk to him, to disclose her autism. She explains,

... 'how I communicate and express myself is very much influenced by the fact that I am autistic', and he looks at me and he goes, 'I always suspected that you had some kind of behavioural issue'.

Shunuli, p25

Heather (p60) notes that there is a real disconnect between equitable laws designed to 'protect' the interests of disabled people and underlying social attitudes and infrastructure. People need to feel comfortable in expressing their own identity if they are to feel a semblance of place-belongingness. Feeling valued and listened to is an essential part of that. They need to feel like they are an integral part of the community, and that their opinions, thoughts and feelings are of concern to the social order as a whole. Any laws that are enacted with the intention of protecting them need to be respected and upheld by the entire populace. As Antonsich remarks, 'the role

of political institutions is not sufficient if the rest of society fails to ‘grant’ this recognition’ (Antonsich, 2010:70).

Successive governments in the UK have made it difficult to attend university for people from poorer backgrounds (Immerwahr, 2002) with the enactment of tuition fees in 1998 (Fact Check, 2019). When she lost her job, Christine needed financial support to pay her rent, which she was unable to claim as a student. This contributed to her decision to leave her postgraduate degree, only months before completing. Patrice was also plagued by money worries. She describes being manipulated into taking out a loan to pay for her college fees and she was assured that the loan was interest-free. Soon after completing her studies, she was billed for an extortionate amount. Kelly, too, was prevented from continuing her studies because she could not afford to pay for them. This implies that the ‘ideal’ student is an empowered consumer: financially stable, or has access to financial resources that, in an austerity-riddled economic situation, many of us do not.

5.3d Failing schools

We have already seen how the school system failed Patrice with their lack of recognition of her struggle. She longs for a system without standardised tests, that didn’t solely ‘cater to the ‘smart’ students that don’t struggle in school’, (Patrice, p4), akin to Super Samantha. Favouring only a certain percentage of students leaving others, who could most benefit from help, behind is a dangerous neoliberal tendency. This tendency is encouraged by the increasing marketization of education, seeing the ‘best performing’ schools (based on the number of students obtaining higher grades) gaining notoriety and funding. The other students, then, are left to fall by the wayside. Ben also notices this point, musing

I think the current system facilitates the same kind of people, and anyone that deviates from that is left in the wilderness. That means the same sort of person rises to the top, which means we have people with a lack of diversity and different qualities with the best education and jobs.

Ben, p15

Charlotte also felt betrayed by the school system which consistently failed to recognise her ADHD and her inattention as a symptom of it. Ben reports issues with what his school believed was ‘laziness’ before his diagnosis with ADHD. He says sorrowfully,

Most reports say ‘has a lot of potential, but doesn’t try’, ‘if Ben put more effort into concentrating then he would be reaching his potential’. Interestingly, the mental health nurse at the diagnosis informed us that she has seen this trend a lot, adults who were

educated at private schools are often mistaken for being lazy when there is undiagnosed ADHD'.

Ben, p2

Ben states that he achieved 10 GCSE's grades A-C, and the top grade was with a teacher who did identify that he has a problem with concentration and cultivated various ways of maintaining his attention. He says his experience at university before the diagnosis was tough, and identifies the lack of support from peers as affecting his self-worth.

I spoke to lecturers and other students but no one really understood, it always came down to 'just do it, just try' what do you say to someone who says, 'I stare at a screen all day, I've tried to break up my learning times, I get distracted, I go off at any opportunity, I've tried working everywhere, there is a deadline in 2 days and I have 6 thousand words', they just say 'just get on with it', if you haven't got ADHD that's pretty logical, if you have ADHD that's very difficult.

Ben, p12

The language of accommodations is inherently normalising, urging students to squeeze into a mould that is archaic and arbitrary. It insinuates that being able-bodied/able-minded is an obligation for one's existence at university to be credible. Rather than consider amending pedagogical practices at university in light of enormous chasms that have been identified with the increasing need for 'accommodations', universities continue to locate the 'deficit' as being inside the individual student. The student then needs to alter their learning behaviours in order to better approximate the undisputed norm. This can be construed as 'the compulsion to effect ableist regulatory norms' (Campbell, 2008). The ideal student is produced through normative, narrow and restraining methods of teaching. This then produces a limited version of 'success', and thus narrowly defines the proportion of the population who are permitted to characterise themselves as 'elite'. As Anton stated, *I almost feel compelled to live up to those expectations... it's not a very healthy motivation is it?* Feeling like you are obligated to morph able-bodiedness in order for your existence to be tolerated has a significant effect on one's sense of self-worth, as we will explore in the next theme.

I will end this theme with a quotation from Kelly, who sums up her experience at university succinctly;

There's only so much you can do before like character development becomes poisonous. It's like one setback after another... Ok it hasn't killed me yet but like it's literally ...it's defeating me. It's like making me miserable. It's like when is the character development enough?

Kelly, p66

5.4i Internalised ableism

Once oppression has been internalized, little force is needed to keep us submissive. 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. (Mason, 1992:27)

As I inferred in earlier chapters, psychology has always had a precarious relationship with disability, as the dominant medical model deals with disability as ‘loss’ and adjustment, and invariably views the experience of disability as tragic. However, it is vital that we follow in the footsteps of authors such as Donna Reeve (2006) and Dan Goodley (2006; 2012) in exploring the very real psycho-emotional dimensions of disability. Interactions with strangers in particular (such as admissions staff or lecturers) can leave a disabled person feeling worthless and invalidated, and can be as effective a barrier to university participation as structural inaccessibility (for example not having the lecture notes in an accessible format). These sometimes small acts of microaggression can cause a significant amount of anxiety. As Reeve (2006:106) identifies, ‘For many disabled people, it is the barriers which operate at the psycho-emotional level which have the most disabling consequences on their lives’. As we can see with Kelly’s urge to educate her classmates about her disability, or Crazy Chorister’s defiant reaction to being called names in the street, disabled people often take on extra emotional labour in an effort to combat the effects of this form of psycho-emotional disability, often at considerable cost to their personal self-worth. To be blunt, in the cultural imaginary disability and university graduates do not go hand-in-hand. For example, I struggled to find any examples of disabled graduates through numerous search engines. There is very little cultural representation of disabled students, and the sentiment that success in the academic world is only achieved by approximating the non-disabled or being incredibly gifted permeates strongly into the fabric of academia. This lack of cultural representation, lack of belief that disabled students will succeed at university, and the struggle to secure appropriate accommodations when at university combine to produce a hostile environment in which a disabled student’s presence in academia is always challenged. This can lead to a number of psychological and emotional reactions, and can play out in complex and often conflicting ways. Retaining a strong identity as a disabled person when the overwhelming onus is for one to approximate the non-disabled wrenches the student in almost opposing directions. For some of my participants, I infer, having a strong disabled identity does not mean succeeding *despite* their disabilities,

which accommodations are conceived to be an antidote for. Rather for them, success is achieved on a different level (which I shall cover at a later stage).

We have seen how the feelings of not belonging in a place or situation can have a substantial effect on the self-esteem and self-worth of my participants, exacerbated by the lack of appropriate support and the reluctance to provide it. My participants discussed the effects of internalised oppression, disability disavowal and the internalisation of neoliberal ableist values which I will expand upon in the following sections. This can lead to psycho-emotional *ableism* – the debilitating and exhausting compulsion to approximate the ideal (non-disabled) student. These of course have particular applicability to my research questions around the psycho-emotional experience of being a disabled university student, and the permeation of ableist norms into the university ethos and ultimately on to the students.

5.4a Internalised oppression

Patrice is a classic example of the internalised oppression that comes from consistently being measured against standardised grading systems. She feels constantly judged not to be good enough, and I have the strong impression that she carries this internal critique of herself into other areas of her life. Ben also recounts a spiral into depression, due in part to his school's lack of recognition of his disability and failure to adequately support him. He narrates,

From 17-22 I lived at my dad's farm, I really didn't do anything... I have no idea, I wasn't out there having fun, I didn't have many friends. I just stayed in my room... this was pretty much undiagnosed ADHD with comorbidities of anxiety and depression. I didn't feel confident enough to do anything at all and hoped that the best I could do is build a small log cabin in a field and refurbish the odd bit of farm machinery to pay for bills and food – that was my life option.

Ben, p 3

This excerpt from Ben's testimony illustrates the effect that non-recognition of a learning difference can have on a person's self-esteem. Ben's frame of reference for success is evidently related to the narrow parameters of standardised grading systems and his teacher's reactions to his learning behaviour. His insinuation that a university education is invariably preferable to building his own house and fixing machinery might be viewed as an example of the high regard given to university education, irrespective of its actual benefits to the student involved. As we have seen, the way that universities are organised with the increasing marketization (Molesworth et al., 2011) actually causes, or helps to cause, significant distress in many students (Turashvili & Japaridze, 2012; Douglass & Raibul Islam, n.d.; Stallman, 2010).

Ben continues with the insinuation that university represents the highest accolade for young people. He maintains, 'if I don't achieve this, I'm stuffed, there are no other options for me' (p12). He explains that he regularly compared himself with others who he felt had succeeded—'they had achieved and had respected jobs' (Ben, p 3). He felt he was lacking in this regard. When he decided to apply for university, he compares himself to the mythical Ideal Student', (the Super Samantha's), postulating that they would be finding the lecture-format of delivering material easy and would be able to absorb information like a sponge. In contrast, he describes 'feeling crushed' by his university experience (p11). His perception of himself as 'less than' does not take into account the failure of his university to structure his learning so that it was accessible to him, not just the few that were adept at this particular teaching style. Ben states that he does not want to pursue further studies if the process will continue to follow the rules of the market in narrowing the experience for students. He describes university as a 'system, a machine – not this nurturing thing which I think it's probably supposed to be' (Ben, p13).

Lilly relates frustration at being treated differently to non-impaired students in her desire to teach. I strongly suspect that this was due to her speech impairment, as she states that it wasn't just a blanket ban on international students. She adds,

You feel certain things, you know, such things reinforce that you're not good enough, less than, you're inferior... this exaggerates the internalisation...

When I have time to think and don't have to write it down then it's very different, when I get less support I lose my confidence and the other thing kicks in and so everything just goes pear-shaped really.

Lilly, p 23 & 29

The idea that things are very easy for other people is a trap that I have fallen into on numerous occasions. Objectively speaking, it is perhaps true that students with two working hands find it easier to type or to carry objects, but the insidious feeling that I am less worthy as an individual with an impairment is infectious, permeating everything that I try to achieve. The knowledge that my efforts will not be as good as (insert any non-disabled person's) efforts is deeply humbling.

Lilly reveals feeling similar emotional states of inadequacy. She relates,

The pressure is immense especially when you're doing a PhD because you always feel inadequate, I was inferior and felt very intimidated by everyone, you know, so, especially if you're disabled the emotion's even exaggerated, you know, and you never, you never live up to everyone else's expectations so there's great inadequacy there, inferiority and internalise that, the inadequacies, so that it affects the whole life and the

preparation, I mean I found doing the PhD those years were like really dark years because I was very isolated doing work on my own and then all these emotional problems with everyone in the department you're now feeling inadequate and unsupported so I think those pressures are caused by very high expectations and pressure put on by the system...

Lilly, p13

Charlotte describes feeling disabled by her experiences with lack of appropriate accommodation, and hostile responses of others to her diagnosis, *not* by her impairment. In Ava's story I firmly suspect that she was engulfed by a compulsion to emulate the norm. Although she did attend an inclusive school wherein being fluent in American Sign Language (ASL) was mandatory, she did not receive any accommodations whilst in mainstream school, and she notes that she 'never felt out of place' (Ava,p1). But it appears that she only subconsciously recognises the spell of compulsory able-bodiedness that she is bound by, reflecting

We learn what is accepted and what is not. Success is when we are able to blend in, not stand out too much and in a way become invisible...

This notion of sameness... a sense of rows and rows of blurred faces... is what emerges when I think about the pressures that occur for individual learners. We spend so much of our time wanting to be like everyone else, yet inside we are seeking people that we can relate to and connect to, which creates a sense of psychic disequilibrium.

Ava, p 4

I get the strong sense that she is talking about herself here, but feels the need to distance herself from the equation with her use of the third person narrative. These accounts extenuate how pervasive the psycho-emotional dimensions of disability are, and how ableism implicitly invades every reach of life. Now we will look at how the beliefs and principles that guide ableist thinking have seeped into the mind-set of my participants, and think through the effect of this on their psychological and emotional well-being.

5.4b Internalisation of neoliberal ableist values

I see a nuanced difference between the notions of internalised oppression and the internalisation of neoliberal ableist values. Internalising neoliberal ableism potentially causes deep psychological wounds that, like the search for the perfect and perfectible body and mind, has no end goal as standards shift and mutate. Internalising neoliberalism –believing the mantras like 'the only barriers are the ones I set for myself' – also has the potential to cause deep psychological and emotional trauma. I see this aspect as a more focused, precise phenomenon arising out of internalised oppression.

We can see from the stories of Kate, Heather, Anton, M and Clare especially that ableism has succeeded in infiltrating the thoughts and ideals of disabled students, however faulty they find them. The ideal neoliberal student is a high achiever, conforms to narrow parameters of rationality, does not challenge the system, and is autonomous, independent, productive and compliant. The disabled student, then, is positioned as an antithesis to this – as someone who needs support or accommodations, and someone who, by their very presence, demands alternative conceptualisations of pedagogical practice. This positioning of disabled students as occupying an unruly and inconvenient space is resisted through disabled students trying to regain status in the social imaginary by approximating ‘normality’. In other words, as is evidenced by the participant’s mentioned above, disabled students often overachieve in order to prove their worthiness. Kate is anxious to be seen as independent, stating that she is able to travel by train alone, and that she doesn’t live with her parents; her parents live with *her*, in her own home (p1). To be seen as independent, as able to mobilise, to make decisions - criterions of the ideal neoliberal citizen – is important to her.

The compulsion to prove that disabled students are ‘good enough’ is noted by Heather (p37) – ‘we have to be twice as good to be counted’. Ava feels this compulsion. She narrates that she incorporated the strong feeling, absorbed from others around her, that she had to over-compensate for her disability if she wanted to be successful;

If I wanted to succeed in the world as a disabled person, then I needed to immerse myself into the hearing world and focus on survival skills for such.

Ava, p2

Clare also believes that she had to put in more effort to succeed as a disabled student, and she attributes her success to her having learnt a range of compensatory strategies to ‘manage’ her dyslexia. She equates her academic success with ‘working hard’ (p1), but then contradicts herself, saying

More effort does not equal better grades as the playing field is not level for people with disabilities/neurological differences who have to overcome access issues, expectations, and teaching methods or even environmental issues such as lighting issues.

Clare, p6

She has clearly absorbed the neoliberal preoccupation with self-responsibility (Sugarman, 2015; Lavrance & Lozanski, 2014; Lupton, 1999; Binkley, 2014), taking it upon herself to ensure that her (socially sanctioned) limitations have been mitigated for, yet perhaps this is a subconscious act.

We can see the desire to approximate the ideal neoliberal citizen played out clearly in M's narrative. He consistently compares himself with other, more financially well-off students and finds himself lacking. M sees education as an 'access pass to certain types of people or lifestyles, or another social caste' (p1). This is a very interesting phrase; it feels as though he is implying here that if you don't succeed in education then you cannot claim the right to belong in a certain set or social group.

He speaks of aspirations of a normative neoliberal citizen; 'being financially independent, as well as the typical things such as being in a relationship and owning and living in my own home' (p2). He talks of cultural capital and universities as a socialisation process, and equates the term 'ability' with social mobility. To him, 'being able' means being socially mobile. Neoliberal-ableist logics of aspiration, of success, of 'getting on' in life infuse education. The idea of meritocracy and social mobility is a very pervasive idea. However, the spell of neoliberal-ableist logics appears to be beginning to wear off for M. He remarks,

I think my understanding of the concept of success has changed dramatically over the last five years or so [after his 'psychotic experiences']. Whereas before it was about becoming and adopting a role as an artist, selling work and being financially independent, I am more content now to say that it's about being happy.

M, p2

It is interesting to note that for him, 'being happy' almost comes off as second best. He states that his social circle encompasses friends that are 'doing something important such as starting their own social enterprises – many of my friends are ambitious' (p4). He is 'both saddened and inspired' by these stories of his peers. He does not define what he means by being 'ambitious', or why he feels that his efforts fail to live up to these lofty ideals. M definitely appears to be caught up in neoliberal ideology. He can recognise it, but still somehow feels both propelled and trapped by it. He remarked that he felt pressure from cultural attitudes and ideologies (p7). I asked him to expand on what he meant by cultural ideology;

Cultural ideology... the pressure to succeed, to be an achiever, of Western values on individual achievement as opposed to eastern collectivism...I think it might be a way of explaining how I got ill and the way I've operated/been in the past. I think it, in part, explains what my value system was and to some extent still is. The idea that you need to achieve achieve achieve and be someone, it's hard to get out of your head.

The idea that you need to be somebody to register on people's radar rather than just being yourself as a reward in itself. I start to give less of a shi now about what people think.*

M, p8.

It sounds as if his experiences of what he refers to as ‘psychotic behaviour’ have altered him in important ways; they have given him the insight with which to recognise that he was damaging himself through his adherence to neoliberal ideology. Aspirational stories are incessantly pumped at us –be fitter, be slimmer, be more successful. ‘Being yourself’ is not enough in this neoliberal economy.

This incorporates the myth of meritocracy - the idea that success is achieved solely by working hard. This myth does not incorporate structural factors such as socio-economic disadvantage, wealth, class, nepotism and heritage. As Crawford (2010:5) highlights, the critique of meritocracy

...illustrates not that ability and hard work do not matter – they are clearly important – but that the criteria by which they are judged are fundamentally distorted by a dominant and elite group in support of core, hegemonic, values that sooner or later lead to a dysfunctional and inequitable society.

Many of my participants seem to have been enchanted by the myth of meritocracy, and believe that ‘working hard’ will ensure them success and respect in the university sphere. This is compounded by the insinuation that disabled people don’t belong at university, causing them to feel that they have to reify their right to exist to sceptical bystanders. This creates psychological anxiety, and can be seen as a form of psycho-emotional *ableism*. Approximate the norm or else! This follows the insinuation that the only way we will succeed in the academy as disabled students is to approximate the norm by having suitable accommodations to prop up our faulty impairments. This is compulsory ablebodiedness. Describing the experience of university as a ‘slog’ or an ‘endurance test’ is evidence of the torture of ableism; no matter how successful you are, there will always be another level that is just beyond your reach.

5.4c Disability Disavowal

Another dimension of internalised ableism is disability disavowal (Shakespeare, 1994; Goodley & Runswick-Cole, 2013; Goodley, 2014). What I mean by this term is where a disabled person accepts the negative depictions of disability, but is eager to disown or disavow the people characterised by those depictions and paint herself as ‘not like *those* people’. We can see this played out in the narratives of some of my participants, notably Heather, Ava, Crazy Chorister and Kelly.

Ava expressed dissatisfaction at how her receipt of accommodations ‘outed’ her as disabled. She discloses,

I struggle with that as on the one hand I'm grateful for the materials, and on the other, I don't appreciate being outed. As a result, it created a social buffer zone as people see that I am different, but they are also struggling that I don't act like a conventional 'deaf person' as I am still able to hear and speak for myself.

Ava, p2

It appears as if she is struggling with the perception of *herself* as a 'conventional deaf person', possibly attributable to the fact that she was mainstreamed for a proportion of her education and perhaps felt the pressure to emulate the non-disabled norm, as she notes that she was the only disabled student in her class. Ava appears to hold low expectations of disabled students, stating

I need accommodations where individuals understand the level that I am at – high-achieving, straight-A kind of student. I often times feel there is a kind of implicit bias towards students with disabilities – such as lower standard of what one needs.

Ava, p2

From her narrative here, I suspect that Ava has internalised negative messages about disabled people, and possibly of herself as a hard of hearing person. She is keen to stress that she has developed strategies to live in the hearing world, and needs to be able to 'pass' as non-disabled. It is important to her that she is recognised as being a high achiever, against the general opinion of disabled students as having little to contribute. Perhaps I am over-reaching here, but it appears that she may hold some of these opinions herself, and is eager to depict herself as 'not like *them*'.

Kelly, throughout her interview and all prior engagement with me, was eager to identify herself as '*high-functioning disabled*' – a total of 11 times in a 104 minute interview. She did not make disparaging remarks about the 'ordinary' disabled, but it was implicit in her testimony that part of her wanted to disown her disability. On page one of her transcript, she refers to 'the CP', as if it's something that doesn't quite belong to her; she is distanced from it. I am also guilty of this disowning my 'failed' embodiment – I refer to 'my arm' as if it's not quite part of me, it's an object that is distasteful, even though I like to think I'm proud (finally) of my disabled identity. This has clear links with Mitchell & Snyder's (2015) term 'able-disabled'. This term relates to 'disability's grudging admission to normative social institutions through inherently neoliberal forms of redress' (Mitchell & Snyder, 2015:35).

Kelly explains that there is a split in America between 'general' education and 'advanced' education, and places herself firmly in the latter group. She states that the students who are in

the general education classes do not habitually pursue further education. She is quite rightly proud of her achievements, but the disavowal of her disability throughout her interview is a poignant reminder of the subordinate value given to disabled lives, even from the perspective of a disabled person themselves (Mitchell & Snyder, 2015).

Crazy Chorister appears to want to distance herself from the reputation of the ‘special school’ she attended, where she doesn’t feel like she got ‘the education I feel I deserve’ (p31). She states,

I, how do I describe it? I could probably learn more than most kids in the school because they were more learning disabled, my education was hampered because I had to go at their pace rather than the pace that would have been more suitable for me so I missed out on the chance to really show my talents off. You know, I hated the label that this has left me with, erm, because obviously when I was at that school it was for children with learning disabilities. I don’t recognise myself as somebody with a learning disability...I very much, erm, hold myself away from that. I have a physical disability, I do not have a learning disability.

Crazy Chorister, p32-33

The vehemence with which she said ‘learning disability’ was startling. ‘I very much hold myself away from that’. She recognises the unfair treatment of learning disabled people, and she is frustrated at how that label binds and restricts how she is viewed socially. This rejection of certain disabled people causes considerable internal dissonance (Deal, 2003; Smith, 2012; Reeve, 2006; Mogendorf, 2013).

Reeve (2006:5) discusses the hierarchy of impairment with the people in her study, with ‘people who use wheelchairs, people with visual impairments and Deaf people I.e. those who sign’ at the top of the hierarchy. This led one of her participants to question her status as a ‘real’ disabled person, ‘or just someone with a dodgy arm?’ (Reeve, 2006:7). This can lead to further feelings of subjugation on one hand and guilt on the other; the sensation that one is potentially taking the entitlements of a ‘rightfully’ disabled person away. Mark Deal (2003) suggests that this may be one of the reasons for potential hostility to be displayed to members of other impairment groups. He suggests that it is also likely that an individual wants and needs to maintain a positive self-concept, thus the need to reject the association with a social identity that has been declared as objectionable. But as Deal (2003) interjected, if there is nothing wrong with having a disabled identity, then why do my participants wish to reject a part of that identity themselves? He also comments that ‘the impairments conform most closely to the norms set

by society, such as acceptance of the work ethic and are not ‘value rejective’, will be ranked as the more acceptable’ (Deal, 2003:900). This sentiment seems to be echoed in my study.

Heather also appears to distance herself from certain groups of disabled people, asserting that perhaps one of the reasons she has had success in her job was that she didn’t ‘drool’ like other disabled people do. When asked about how people reacted to her disability, she replied,

By and large it’s been positive, but that’s because I can communicate effectively, I think, I may have cerebral palsy but I can manage in situations where I can, you know, I have a degree of flexibility and I don’t drool or, you know, it’s not that kind of off-putting stuff that people who haven’t had a lot of exposure to disability tend to speak about.

Heather, p21.

She refers to the time when she was in ‘special school’, and ‘never saw any other kids apart from disabled kids’ (p22). Her fear driving her zealous pursuit of education, if we recall, was that ‘if I don’t perform really well I’ll get sent back to special school’ wherein any qualifications she received would not be recognised outside of this remit, and her academic future would thus be severely limited. She discloses,

Escaping, escaping special school was, er, like if I had stayed there that would have been the most negative impact on my life.

Heather, p49

Heather refers to ‘special school’ as if it were a trap, an incongruous device that was solely concocted with the intention of sifting and dividing young children from a young age purely on account of their perceived ‘difficulties’ (Kaufman & Hallahan,1995; Goodman & Bond, 1993; Becker, 2009; Slee, 2013). There has been much discussion of the limiting nature of special education. Slee (2013), for example, talks of his friend and neighbour who has been placed into the ‘opportunity grade’; an ironic name as it formally shut-off opportunities for those assigned to it. He muses, ‘An outpost of segregated special schooling within the mainstream, the opportunity grade, was for those who did not belong to the regular classroom. It was also an official ending of opportunity’ (Slee, 2013:902). This echoes what Heather fears it would have been to her.

We can see from this brief exploration of internalised ableism that it has far-reaching qualities; the ability to infect the minds of even the most critically reflective disability scholars; and, as Deborah Marks (1999) warned us, has the power with which to reinjure us every single day.

This chapter has explored my participants responses to the questions posed in Project One, and I have made a number of allegations around the exclusionary nature of neoliberal ableist tertiary education. My first bone of contention was highlighted by my exploration of belongingness. My participants dealt with both high expectations and poor prospects, enforcing a sometimes excessive degree of emotional labour in endeavouring to dispel the low status of disabled people. They were beset by the expectation that they ‘wouldn’t amount to much’, and dealt with rejection on often on a daily basis. Additionally, they had to put up with the dysconscious ableism surrounding them: in the architectural landscapes of university buildings; in the formation of the library; and in access to knowledge. The second bone of contention was explored through the failure of universities to provide adequate support to disabled students. This was highlighted through the increasing tightening of eligibility restrictions to disabled student’s allowance; the reluctance to grant funding; and ability privilege not being recognised. I ruminated on the additional emotional labour (Hochschild, 1983) of self-advocacy and negotiating access, and the potential this had for making my participants physically and emotionally sick. This was combined with and exacerbated by ableist ideals governing pedagogical practices. ‘Teaching to the top’ (Dwerk et al., 2014; Duckworth & Seligman, 2005) – to the imaginary Super Samantha’s (Dolmage, 2017) of this world - left many of my participants to feel left behind (Goodley et al., 2019; Mitchell et al., 2014). ‘Disabled students’, neoliberal ableist university practices dictate, ‘must develop a range of compensatory strategies in order for their very presence at universities to be tolerated, let alone celebrated!’. This was emphasised by my participant’s efforts, often fracturing their already fragile sense of self-worth. I then demonstrated the febleness of legislation without proper societal backing, and implied that this could sometimes do more damage to the self-esteem and self-respect of disabled students. I also implied that schools themselves could corrode student’s self-worth by not recognising calls for assistance, and instead labelling students as lazy and disruptive. Combined together, these often implicit and dysconscious pedagogical practices underscore the insistence of compulsory able-bodied- and mindedness.

I proposed that this insistence on compulsory able-bodied and mindedness infiltrates the psychological and emotional mind-sets of my participants, resulting in internalised ableism. Through the lack of disabled role models in cultural representations of university graduates; the narrowing of pedagogical delivery; the insistence on perpetuating the mythical ‘ideal student’; and the unspoken positioning of the disabled student as the antithesis to this, my participants felt a sometimes overwhelming pressure to emulate the ‘norm’. This left them with

considerable internal dissonance. I argue that we are living in an era of fundamental belief in the power of the self-actualising tendency. What this means is a simmering but pervasive belief that we can, through the power of our minds, effectively change our circumstances. This contemporary cultural motif is linked with ‘broader self-help discourses that define wellness as a personal, obligatory, and moral achievement to both self and community’ (Lavrence & Lozanski, 2014:77). This leads me to ask the question, ‘What effects does an ideology that prioritises health and wellness – and, significantly, apports blame onto those who do not appear to possess these attributes – have on the psycho-emotional welfare of individual students? The entrepreneurial project of knowing and continually upgrading (Lavrance & Lozanski, 2014) oneself, especially in relation to one’s educational achievements and employability, has become a central feature of neoliberal efficacy. I argue that these values have seeped into the mind-sets of my participants and have become lodged there, intruding on their self-worth.

With reference to my participants, it seems that they were both propelled and trapped by the values of neoliberal ableism. This led some of my participants to develop an uneasy relationship with their own embodiment, to disavow (Shakespeare, 1996; Goodley & Lawthom, 2013; Goodley, 2011) their disability in order to align themselves more closely with the dominant group. This denotes a troubling relationship with neoliberal education, and the issues that this chapter has flagged up signify real cause for concern. In the following chapter, however, I position disability as a productive force, and think through the insights that disability as a concept can bring to developing new ways of being.

CHAPTER SIX: INVIGORATING POSSIBILITIES

6.1 Overview

Our support systems are more visible than the next person and some forms of support are socially accepted and others aren't...

Heather, p28

So far the report for Project One has made rather depressing reading. This would seem to confirm that university is not a suitable place for disabled students; that they will inevitably experience hardship and misery and should therefore, on the ground of protecting their mental health, desist from attending. However, some of my participants had positive experiences at university, mostly due to levels of acceptance and flexibility from university staff, and from finding within themselves deviating standards to judge themselves upon that refute the astringency of conforming to neoliberal ableist norms. Therefore the next theme I compiled from the narratives of my participants is when supports do work. The following chapter will incorporate participant testimonies of the benefits of specialised primary and secondary education, proceeding to explore which particular supports my participants received well in the university setting and how they found them useful. We will proceed to explore disability as a potential site of possibility, then moving on to a summary and discussion of the themes identified in Project One.

6.2 When supports do work

On occasion my participants reported positive experiences within their educational realm, and the following is a summary of these reports.

6.2a Specialised education

Although the focus for this project is on experiences within Higher Education and universities, some of my respondents reflected on their experiences throughout their education. Three of my participants expressed the benefits of being educated in a way that was cognisant of individual needs and tailored around providing support specifically adapted towards individuals with particular impairments. Ava attended a school wherein the enrolment requirement was that each student be fluent in American Sign Language (ASL). This then allowed a fusion of deaf, hard-of-hearing and hearing students to attend. The style of teaching at that institution was delivered in a way that was accessible to a range of students, as the lessons were delivered orally with the interpreters translating the classes into ASL. Ava declares that this style of teaching was innovative in that 'everyone could interact with each other' (Ava, p1).

Additionally, it was a common experience to be taken out of classes to attend, for example, speech therapy. Ava explains,

Those of us who were pulled out for speech therapy, it wasn't unusual as it was not the scenario where you are the only kid that is being pulled out or the only kid in the classroom that needs accommodations.

Ava, p2

This anaesthetises the disconnect and isolation that often accompanies being manifestly marked as different and in need of repair through the need for alternative treatment. She remembers the teaching style in mainstream education as being restrictive and tedious, causing her to fall asleep, in stark contrast to the 'active-based' learning that she experienced whilst in inclusive education. Ava has carried this on to influence her pedagogy as a teacher. This in a way is a positive aspect of experiencing schooling in both mainstream and inclusive settings.

Abdu reflects that the main goal at his boarding school as he saw it was to teach the students how to live an independent life and how to integrate into society. This smacks of normalisation yet again; the notion of compulsory sameness and that it is the disabled person's responsibility to mould themselves into a citizen that is suitable for society, not the other way around. Nevertheless, Abdu saw benefits to this method of instruction. He reminisces about his time at boarding school, reflecting that he felt like there was a community spirit there, making him feel confident and understood, 'a sort of togetherness' (Abdu, p16). He refers to his boarding school experience as a 'unique culture' (Abdu, p17) that shaped the way he perceives education and society as a whole. Through learning about the non-acceptance of blind people in society, and his experience of community/belongingness he was able to decode the implicit rules and act appropriately for society to deem him acceptable, whilst knowing that he was still worthy. In this way, the scourge of ableism does not appear to have infected him as much as my other participants. Perhaps the strong feeling of community belongingness, coupled with the fact that he is the eldest son, gave him the armour with which to protect himself against society's negative representations of disabled people so that he did not internalise these harmful images (Müller et al., 2018; Waghorn et al., 2004; Lomosky & Lazarus, 2001).

Lilly talks about her fortuity in being able to attend a college for the blind in England, after being restricted by an inaccessible school environment in her country. She was appreciative of the small size of the college, only 160 students, so like Abdu 'everyone knew each other, it was a very friendly place' (Lilly, p6) that was specifically designed to incorporate the needs of blind students. As it was a college for the blind operating in the disablist society of the time (around

twenty years ago), she feels there was less pressure put on both the teachers and students to perform to certain standards or to achieve certain targets (Winzer & Mazurek, 2017). This meant that the staff had more time to devote to each student (Vaughn & Linan-Thompson, 2003), ensuring depth of understanding. Lilly maintains,

When you have less number of students it's much easier to support. Giving them more time to actually, erm, help their communication and their understanding.

Lilly, p19

Time has been a factor iterated to me by a number of my participants, insinuating that if teachers or lecturers had more time to devote to each student, their depth of understanding and engagement would be far greater (Katzman et al., 2020). Heather draws on her experiences as both as a student and as an academic to succinctly express her reservations with being assessed according to strict time schedules. She asserts,

Defining the speed of thought as success... it's problematic for people with disabilities because whatever disability we have, whatever impairment we have, I don't care, it takes more time. And because it takes longer to do it doesn't mean that you shouldn't do it or you're not capable of doing it, and that in no way reflects on the quality or standard of what you're doing it just takes longer right?

Heather, p 32

6.2b Accommodations in a university setting

Some of my participants reported having positive experiences of accommodations, particularly if they were delivered on a personal scale. For example, Charlotte described having trouble figuring out how to do something on a university website. She explains that her tutor sent her a step-by-step video link explaining the process, with no fuss or refusal to offer support on the grounds that this would give Charlotte an unfair advantage that other students would not receive. Charlotte appreciates the support that she is now afforded – such as receiving one-to-one mentoring to ‘keep me organised’ (p5) and a voice recorder so that she doesn’t forget what was said in lectures. Heather also notes a similar effortless attitude to providing support from her former tutor. She notes that as his office was slightly inaccessible for her, he suggested meeting at a place of her choosing for supervision sessions, and even offered to format her PhD for her – something that would have taken her hours to do. These anecdotes of supports are minor, but significant for my participants in the hours of frustration they avoided. They can be

seen more as small acts of kindness that make a big difference in the lives of disabled students.

As Charlotte remarks,

I appreciate the recognition of the difficulty and the willingness to support it. I don't appreciate pretending it's not there, nor pointing it out and using it as a reason to expect me to fail.

Charlotte, p5

M similarly praised his lectures response to his disability, saying they approached him individually to ask if there was any way that he felt they could support him. Like everyone on his course, he has a personal academic advisor. She offered to meet with him separately and privately if he needed further support, and he has availed himself of the mentoring assistance offered by the disability support services. He felt appropriately and sufficiently supported. Djodjo equally felt supported by the staff at his university after he became disabled whilst pursuing his Masters. His lecturers always ensured that his lectures were accessible, to the point that if his interpreter was late or failed to arrive, he would make the decision as to whether or not the class would be cancelled. Ben affirms that shortly after his diagnosis, he received funding for a mentor, a note-taker, a laptop, assistive technology (he doesn't specify what) and 'reasonable adjustments' for his placements. He appears to have been questioned about the fairness of these accommodations as he adds,

The way I try to explain this to others is that people with ADHD are on a -30 out of 100% in a normal setting, everyone else is on a 0% and must achieve 100, by reasonable adjustments in place it ensures that ADHDers are on a 0% like everyone else.

Ben, p 4

Ava did receive some support from the disability services in the form of a CART (Computer Aided Real Time Transcription) transcriber, although she implies that she would have preferred the use of an ASL translator. 'The impression I got', she discloses in her email interview, 'along with confirmation from other deaf friends later on, CART/transcribers was cheaper and more 'encouraged' (more enforced) than ASL interpreters. It didn't matter if a person grew up with ASL. It was straight about what was more cost effective' (Ava, p2).

Some of my participants take medication to ameliorate their conditions, and they feel that this has a more beneficial effect than any accommodations. Charlotte feels that this is a lifeline for her. She says emphatically,

The medication has allowed be to learn things that I could never do before, like carrying a mobile phone, using a diary, taking my cash card out with me every time I go out, mostly turning up in the right place on the right day. I'm still in total chaos each morning until my meds kick in, or if I forget them, but generally things are good.

Charlotte, p5

Ben concurs with this view, stating that his medication has helped him to be able to categorise things in his head. He mentions that his diagnosis has significantly improved his relationships in his personal life as well, and has been able to transfer some of the academic accommodations and recommendations he established, such as list-writing, into his personal relationships.

M does not specifically mention how he feels about his medication, but does suggest that his medication prevents his 'psychotic episodes' which he finds frightening and upsetting. He indicates that his medication helps to regulate his emotions.

Anton's narrative around accommodations in the university setting is slightly different. He began by inferring that the only accommodations he received were the use of his laptop and a separate format for his high school history exam. When he thought more about it, he was able to list a few others – extra time on assignments, the use of a taxi service, and the provision of a personal assistant that he maintains were actually central to his ability to complete his courses (Dolmage, 2017). He realises,

You see, I don't even notice such things... I remember when I first spoke to one of the disability advisors at the university, and he was like, 'can you tell me a bit about your needs? And that's something I'm not used to speaking about and not really used to thinking about... you don't really get introduced to thinking about those things... None of this was available in Poland.

Anton, p13

I suggest that Anton's response here can be partially attributed to his internalisation of ableist values, and his drive to 'surpass' able-bodied people in his academic endeavours. This, if we recall, was constructed around his indoctrination into compulsory ablebodiedness, and his lack of ability to see the world in a different way. Now, as he is being introduced to alternative theories and ideologies, Anton is beginning to realise that able-bodiedness is not in fact compulsory (despite cultural implications to the contrary), and there are indeed many rewards to be reaped from the awakening of alternative ontological viewpoints. We will return to this

sense of how the experience of disability can reconfigure and revitalise stale ways of being in the world in the next theme.

A note on the concept of dependency

Let us pause briefly here to examine the concept of dependency implied by the use of accommodations. The concepts of independency, autonomy and self-reliance are explicitly lauded in university settings, reflecting the ideals of the ideal neoliberal citizen (Weicht, 2010). Dependency, then, is constructed as an inverse and inherently undesirable condition. Independence and autonomy are constructed within the university ‘as unproblematic and universally desirable goals’ (Fine & Glendinning, 2005:602). Dependency, rather than being viewed as a necessary social condition, is held to be entirely negative and those deemed to be dependent must of course actively seek to reverse this adverse status (Fine & Glendinning, 2005). Dependency is an essential human condition that is life-sustaining and complex, and the denial or rejection of this reality is a symptom of the neoliberalisation of our current society and the obsession and idealisation of independence and autonomy. In other words, independence and autonomy are socially valorised phenomena, and dependency is thus a socially spurned actuality. Moreover, dependency is seen as an individual attribute, not a product of unfavourable social relations (Weicht, 2010; Fine & Glendinning, 2005). The concept often denotes an irksome burden on the part of the person needing help (Shakespeare, 2000) and suggests innate deficiency that can only be ameliorated by the help of a benevolent non-disabled person. This perception of dependency as negative should then, in this light, be amended by public policy measures such as, for example, the provision of academic ‘accommodations’.

However, as we have seen, asking for accommodations can often take a considerable emotional toll on the disabled student. They are begging for scraps which they then have to feel grateful for. It involves the student chronicling all their difficulties, fixating on their deficiencies and focusing on what they cannot do, and encourages a power discrepancy in favour of the altruistic benefactors – the universities. This then ignores or side-lines any responsibility they have to ensure tertiary education is accessible

Shining a Social Model light on this phenomena, we can see that the desire to ‘accommodate’ the individual disabled student in order to approximate or pass for the ideal student is akin to the Medical or Individual model way of perceiving disability. The Social Model perspective, presumably, would propose that changes were needed to the entire structure of academia in

order to allow all students to effectively utilise its resources. I am not, by any means, inferring that accommodations should not be given, or that they are not appropriate in certain situations. Certainly, the narratives of my participants have shown that the provision of accommodations have proved to be a lifeline for students and have enabled them to persist in their studies more smoothly and effectively. But by applying a social model perspective to the analysis of accommodations in academia, we can see that this policy serves to reinforce the exploitation and discrimination of and against disabled people—even if these policies involve considerable resources being redistributed from the non-disabled to meet the supposed ‘special needs’ of disabled people (Smith, 2001)

What I am suggesting is that instead of continually focusing on ‘levelling the playing field’ by introducing accommodations, more focus needs to be on the ways in which the adherence solely to conventional pedagogical practices can disempower learners at any level and on invigorating alternative methods that consider the learning behaviours of a greater range of students. This begins to address my third research question: What alternatives could be conceived of for the future of education that goes beyond the neoliberal ableist agenda? Incorporating the reality of dependence into the core of our educational practice instead of vehemently pretending it doesn’t exist would begin to integrate notions of interdependence, of relationality, and of interconnection. My participants continually narrated an urge for education institutions to move towards these attributes. This, hence, is the subject of my next theme.

6.3 Disability as productive

Sub Rosa

Fighting to establish self-respect ...
Not the same, but different ...
Not normal, but disabled ...
Who wants to be normal anyway?
Not ashamed, with heads hanging,
Avoiding the constant gaze of those who assume
that sameness is something to be desired ...
Nor victims
of other people’s lack of imagination ...
But proud and privileged to be who we are ...
Exactly as we are.

(Colin Cameron, Tyneside Disability Arts, 1998; cited in Swain & French, 2000:580)

As this poem, drawn from an article by John Swain and Sally French in 2000 entitled, *'Towards an affirmation model of disability'* shows, disability is not inherently negative. Contrary to the perception of disability as a personal tragedy to be endured, many disabled people, like Shunuli for example, take great pride in generating and producing a non-conformist identity, of which disability is a part. The affirmative model writes both disability and impairment as progressive, and 'encompasses positive social identities, both individual and collective, for disabled people grounded in the benefits of lifestyle and life experience of being impaired and disabled' (Swain & French, 2000:569).

I acknowledge that in these times of extreme neoliberal ableism, it is difficult to see that disabled embodiment can bring a lifestyle that is empowering. Nevertheless, as my participants and I will show in the following theme, disability can instead be seen as a productive force, in that it calls attention to and deflates the preferred neoliberal citizen of modern times. It also offers us a way out, a way of escaping the constrictive and oppressive rubrics of normative performance by offering other paths formulated as a response to living within Crip/queer modes of existence (Mitchell & Snyder, 2015). To 'dis' something is to find fault or critique it. I suggest that this is what is happening with my participant's reaction to the neoliberalisation of university education. What I have garnered from my participant's narratives is that they just want to exist with value and dignity, and that this can best be achieved by holding themselves to different standards. We can see from the normative characteristics of the 'preferred neoliberal student' – autonomous, independent, separate, individualistic, self-contained, and self-sufficient – and, by association, detached, narcissistic, self-centred and self-serving – that these are inherently troublesome attributes to instil into our education system. Valuing reciprocity, interconnection, interdependence, acceptance, tolerance...these are the words that my participant's expressed as to the direction of pedagogical practice of a truly inclusive society (Mitchell & Snyder, 2015).

We will begin this section by focusing on two narratives in particular – Anton's and M's – as they are most expressive of a change in ontology from the strangulation of neoliberal standards to a more open, receptive stance that incorporates a more collaborative way of being in the world. We will also direct our attention to Shunuli's, Charlotte's and Ben's narratives as they are evocative of stimulating an alternative sense of belonging that reifies disability instead of suppressing it. Then we will acknowledge how my participant's 'played the game', using the inside knowledge reaped from their experiences with disability to their benefit. We will proceed to focus again on the rejection of the neoliberalisation of universities in my

participant's accounts. Next we will open up some alternative definitions of ability and success, and explore what following these alternative definitions might mean for the future of the academy. Finally, we will consider some of the recommendations engendered by this study for the future of university education that goes beyond neoliberal ableist ideals.

6.3a Breaking free –discrediting the neoliberalisation of university education

Anton's narrative is interesting here. He reports wanting to be 'as close to normal as possible' and he admits to having 'a very strong sense of having to, or wanting to be, more accomplished than your average able-bodied person' (Anton, p13). As he has become more engaged with the concepts of critical disability studies however, Anton has begun to question this compulsion. From a young age he was told that he must approximate the 'norm' if he had any hope of being a success, but it is beginning to dawn on him that this is not the case. He doesn't have to prove himself in order to be respected, nor does he have to compete in the way that he was taught to do. However, this internal questioning propels him into a quandary of confusion. He admits,

It seems that, however misguided the purpose was of, erm, like transcending the, or, or being better than your average normal person, it was a purpose nonetheless.

Anton, p13

Now, armed with the theoretical concepts of critical disability studies he is beginning to see the world, and his place in it, through new eyes. I have written elsewhere (Daniels, 2013) about the difficulties of having a strong politicised disabled identity *all the time*, and Anton appears to be feeling this sentiment acutely. He talks of the dichotomy between his writing for his PhD, in which he adopts a strong affectation of himself as a proud and sexualised disabled man, and his life, in which his motivations and convictions are not so clear cut. He therefore feels like he is being disingenuous in his writing, and questions his place in the academy. Anton's dramatic overturn in ontology has thrown him into a precarious and uncomfortable position, wherein the forces of ableism clash with the forces of identity politics. If we recall M's testimony, we can see that he is following a similar path. His change in ontology appears to be a more gradual process, but to me it symbolises a breaking free of the strangulation of neoliberal ideals. M appears to have been strongly captivated by these ideals, and so perhaps for him the release from them will be a slow but steady development. If we recall, M states that he is 'starting not to give a shi*' (M, p8) about what other people think of him and to hold himself to different standards, conceivably attributable to his experiences with disability.

Shunuli developed a firm radicalised and politicised disabled identity – or Crip identity (McRuer, 2006) - in her teenage years, perhaps as a retaliation to her conservative upbringing. Throughout her interview with me she appears to hold strong to this position, possibly encouraged by her position as a disability rights advocate in her university and her regular association with other disabled people. This extenuates the importance of a community in adopting and maintaining a positive disabled identity as it acts as a barrier against the flood of negative ableist ideology that society is bombarded by. Charlotte and Ben’s narratives both echo this sentiment. Charlotte is proud of her identity as non-neurotypical, and incorporates it into her life at a fundamental level. She is part of a home-educating family, and this is part of her wish to surround herself in a community of like-minded people. Ben expresses relief at his diagnosis, and indicates that he feels a sense of warmth and well-being within his disability status. He states,

Suddenly I had this new identity, I was Ben, but I was Ben with ADHD, which now made complete sense to Jenny (his partner), I told my family and friends.

Ben now feels that he has an explanation for his past behaviours, and to why he never felt like he belonged prior to his diagnosis. Ava’s narrative is symbolic of the trait of playing the game, and her experiences both inside and outside of disability reflect her ability to recognise the futility of measuring oneself against normative standards. She asserts,

I think part of ability means being able to play the game. Being able to figure out how the system works and use it to your advantage or not to your advantage.

Ava, p4

Ava’s experiences both as an outsider and an insider to disability have enabled her to perceive a nuanced reality. Abdu similarly discloses a wily ability to comply with the tacit rules of ableist society by mimicking conformity. He states,

You should use the gaps in a sense if you get opportunities you shouldn’t pass them and you should really show them that you are the person that they want to have, that means that you need to create yourself into their requirements even if it’s not ok for you.

Abdu, p21

Many of my participants identified problems with the increasing neoliberalisation of university education. Heather states,

The academy is turning into a business structure right and they're defining success on a very narrow, very narrow scale right? It's sort of a narrow understanding of what education is, what success is, and, erm, there is no space left for critical thinking really. It's like what do I need to pass the test?

Heather, p31

Charlotte concurs:

I think the goals of the people currently in charge of education (in this country) are more about controlling and manipulating children in order to be able to control the adults they will become. Children constantly have to compete against each other in ableist and almost constant testing and ranking. Policy seems to be to further disable those who learn in ways that don't conform to this approach, and keep power in the hands of the wealthy and make sure everyone feels it's their fault if they don't 'achieve' in their system.

Charlotte, p2

Ben agrees with this dire description of education, saying

I believe most lecturers or educators set out for the most rich learning experience for students. I'm also aware of the systems that are in force behind this like deadlines, realities of life, meeting quotas, finance etc. For instance, I know that the university gains money for the amount of places filled and although fulfilment of a rich education is important, marks are also important... so at this point I see university education as a system of box ticking, a game. Me trying to really understand a theory, so completely, deeply and in a rich way for my learning experience should be the goal but I feel the real goal, the one I strive to get is the most solid, most superficial degree of information to regurgitate and meet the standard that is required. I quickly learned to put my head down and get on with it.

Ben, p7

Ben is clearly trying to modify himself into the ideal neoliberal student (Mitchell & Snyder, 2015) – hard-working, efficient and compliant. Moreover, Ben asserts that by focusing solely on arbitrary markers of success, educators are missing out on other, to him more fundamental qualities that should be counted. This is in reference to his placement experiences in a healthcare setting. He insinuates that the people who gain employment are the people who have succeeded academically, regardless of more personable skills such as approachability, empathy, relatability and so on.

Christine feels that the marketization approach (Molesworth et al., 2011) to education made her feel like she was on a conveyor belt, with no interest in her as a person. 'I feel the driving factor was money, getting the people on the course, you know, so they're there, they've booked

all these people on, you need to get through cos there's a new set coming next year...'
(Christine, p14)

She states dejectedly,

When the lecturers found out I had a disability, well you've got ticked off (laughs) now, I'm just on the side of the road. I don't think I'm a thought in anyone's mind whatsoever. Just think time's moved on now and I didn't make it...

Christine, p29

Anton refers to his experience of education, even at Master's level, as a series of hoops to jump through. He declares, 'I just received each and every essay as a task to be completed, right up until the point of my dissertation' (Anton, p21). He yearns for an approach to education that could be seen more as a form of knowledge immersion, a means of saturating oneself with a multitude of theoretical concepts and ideas, and truly engaging with it on one's own terms without the pressure of time restraints. Lilly and Heather also lamented the pressure of time and its restraining influence on in-depth, authentic knowledge generation. Djodjo wishes that there were 'more room for exploring my potential rather than being forced to follow a rigid standard' (p4). These narratives underscore the deep fractures caused to an education system that should be a 'lovely, nurturing thing' (Ben, p13). This leads smoothly on to some alternative definitions of ability and success generated by this study.

6.3b Other ways, other means

Many of my participants found the prospect of discussing the concept of 'ability' to be uncomfortable, suggesting that the dominant depictions of *dis*-abled people in the social imaginary, and the sense of themselves as embodying the antithesis to this – are pervasive and demoralising (Goodley, 2014; Campbell, 2008). It is also a difficult word to define without referring to its supposed binary (Goodley, 2014). In the context of this study, the tendency was for participants to give very normative definitions. However, some of my participants were able to define it in unusual ways. For example, Charlotte espoused,

Ability is a system of supporting each other that enables everyone within society to live valued lives.

Charlotte, p2

This interpretation of ability has definite transformative potential. It is inspiring to think about the dramatic changes to our societies if this ontological perspective were to be widely embraced. Another view comes from Ava:

Everyone has ability. The question is more about who gets heard, who gets respected, who has the most credibility and etc....

Ava, p3

This underscores other forms of oppression, such as oppression based on gender, class, race or creed. The idea that some people are 'heard', (listened to, valued) and others are ignored has salience in the context of the arrangements of the university. For example, Abdu maintains that he 'was not consulted, not taken into account' (p13) regarding the inaccessible way his lectures were delivered. He continues,

And the way the libraries are organised the physical accessibility... this is this is sort of a practical elimination which is bringing this. The question we should ask is this; who designed this arrangement of libraries? Who designed the way the university is?

Abdu, p13

Abdu leads us to the fundamental questions that should be addressed through engagement with disability studies. We can see these issues as underscoring the oppression that disabled people have been subjected to over the years, but we can also begin to think *productively* about these questions to envisage ways that they could be done differently. What I interpret Ava's insinuation here is that ability is only in the hands of the few, the privileged, the elite. Perhaps in this vein it has little to do with impairment, and more to do with power. Christine continues along a similar vein;

Ability to me means being in the favoured group. Because then you are afforded ability, everything is tailored around you [like Super Samantha] being able to do what you want to be.

Christine, p20

Shunuli is highly uncomfortable using the word 'ability', and

...when I do use it I'm referring to specific concrete things like the ability to make a cup of coffee. You might have that you might not...the ability to toilet without someone else's help, it's a concrete thing that you do or you do not have the ability to do, and it doesn't mean anything about your value or worth as a human being.

Shunuli, p47

Ability is a social construct (Kramer, 1991; Goodley, 2014; Ruiz, 1991; Rosenholtz & Simpson, 1984). There is no definitive definition that is not socially, culturally, historically and economically created (Goodley, 2014; Campbell, 2003; 2008; 2015; Wolbring, 2010), and it is tied to assumptions based on race, class and gender. Shunuli is legitimate in her assertion that it should not ‘mean anything about your value or worth as a human being’ but the obsession with independence in neoliberal societies has created the assertion that being able to perform these tasks is *wholly* indicative of one’s worth as a human being (Cherney, 2011; Campbell, 1999; Wolbring, 2010).

6.3c Disability as creative – benefits and dangers

Heather prides herself on her capacity to thrive under difficult circumstances. She states that she is aware that there are some demands of her post that she simply does not have the energy to do, and so she works collaboratively to fulfil these requirements.

People that don't know me well think that I'm exceptional because of what I do and I explain that no I'm not exceptional but I'm able to manage in situations where people don't expect me to show up and, erm, you have to use creativity to, you know, live your life. I don't fill out grant proposals because that takes too much time and energy... a lot of my research is unfunded. I apply for smaller projects because I can handle them... so I'm aware of my own bodily geography. ...maybe that impacts on my career path but so far I've been ok. I think you have to be realistic about stuff. So what I do I work in partnership with someone else, so we get the work done and everybody brings something to the table right?

Heather, p25

Kelly follows a similar method of appraisal. She reveals,

Ability would be defined as methods of compensation. For example, you and I are disabled, we're high functioning physically disabled but I'm sure you have figured out how to do things by strategizing and thinking outside the box. What I'm doing is I'm overcompensating and I'm figuring out alternative solutions and I'm resourceful...

It's what you and I and people like us have done we've worked hard and we've identified our weaknesses and maybe we've identified our weaknesses first which have led to identifying our strengths and then we figure out other ways around them. We're problem solvers that's all.

Kelly, p 52 & 53.

However, I feel the need to move beyond the ‘disability as creative’ rhetoric. I feel that conceptualising disability in this way is too restrictive. What if you are not creative? Does that

mean that you have ‘failed’ again? If I cannot find a way around a certain problem by thinking ‘outside the box’ or coming up with alternative methods, does that mean I am to be doubly rejected? This version of disability acceptability is problematic in the way that it includes some disabled people but discredits others. It is certainly true that many disabled people are indeed creative, and have found unconventional ways of doing things that are often a necessity in order to live in a world that was not made with their needs in mind. But valuing people based on their levels of creativity is tantamount to the restrictive ideals that this thesis urges society to leave behind. Instead, I would promote an advancement of the kind of society that Charlotte values; one in which ability is judged on providing, individually and collectively, systems of support to ensure that everyone in that society lives valued lives.

6.3d The concept of resilience

The concept of resilience from a critical disability studies perspective takes on a different character. Ungar (2005), Hutcheon & Wolbring (2013), Hutcheon & Lashewicz (2014) and Runswick-Cole & Goodley (2013) in particular have criticised the normative understandings of resilience from an ecological position, and have argued that taken in this context, the concept of resilience excludes the lives of disabled people. As Runswick-Cole and Goodley (2013:67) assert, ‘disabled people who are considered to have ‘achieved’ in a ‘normative’ sense or to do the things that non-disabled people do are automatically considered to be ‘resilient’’. This leads us to interrogate this concept. Disabled individuals do not have the ability to ‘overcome their lot in life’ (Runswick-Cole & Goodley, 2013:69) and so do not, therefore, meet the terms generally associated with ‘resilience’. However my participants displayed resilience *as resistance* in many different ways. Every single one of my participants stated that they would not change their educational experiences as it has made them who they are. Through enduring hardships, they have learned ‘resilience’ and tenacity. For example, Kate asserts that her experiences of education

made me a more grounded person... I’m not afraid to push myself if I know that I am capable of achieving. I have applied this philosophy throughout my daily life now outside of education while running my business and how I view things in the world. I never give up my philosophy is you don’t know until you’ve tried it.

Kate, p10

Charlotte reveals that the restrictive nature of conventional education has not succeeded in repelling her insatiable desire to learn.

Education has both freed me and trapped me, at different times in my life. I've literally looked on at 'education' happening around me as I was thrown out of the classes I disrupted. Maybe that's why I became a teacher. Maybe that's why I need to keep learning new things.

Charlotte, p5

Lilly expresses how her exposure to a range of educational institutions with vastly fluctuating levels of support have enriched her life.

I think even the challenges I faced in my education made me the person I am, you know, so I'm actually shaped. I mean it would have been easier if it was less challenging but as I said it's made me more flexible, to be more, erm, to think more solutions and to be more mindful of different barriers.

Lilly, p25

Heather holds similar views of how the education system has shaped her;

It's defined me in a very positive way. I think, I know it sounds weird, but the negative experiences I've had in education have made me stronger as a human being and made me see even more clearly what needs to be done and I think as a disabled person being in this situation I have to pay it forward in some way. I think all these extra hoops or whatever you want to call them have made my life so much richer, and so much more, I'm able, I mean like I've said before disabled people are so creative and so adaptable that I wouldn't have changed a thing. Yes it was miserable at the time to go through some of that stuff but at the same time added depth and dimension.

Heather, p55

These examples reveal that rather than hanging their heads in shame, or wishing that they conformed to normative able-bodied standards, my participants found pride in their ability to take arms against a sea of troubles and turn them into moments of possibility. The experiences of disablism and oppression have not succeeded in squashing the spirits of these particular participants, but that does not eradicate the possibility that the forces of ableism, combined with the forces of neoliberalism, can erode the psychological and emotional well-being of individuals, slowly grinding down their self-worth. These forces can be described as dysconscious, operating under the radar of what is overtly perceptible, but are nevertheless potent operations that have the power to arrest the prosperity of disabled people.

As my participants have shown, we need to attend to the socially and culturally produced manifestations of resilience as resistance in disabled people's lives. My participants have antagonised here their resistance to being defined as 'normal'. In this way, resilience is not necessarily found in 'strength of character' and/or 'ability' to 'overcome', but in the creative ways of resisting normativity, and it 'becomes an opportunity for individuals and communities

to dwell in difference, and to connect and belong in new and creative ways' (Hutcheon & Wolbring, 2013:5).

6.3e Recommendations

My participants all saw a great discrepancy between what the goals of education should be and what they are in neoliberal societies. From their testimonies, I garner that the goals should be around enriching the student by creating deep and meaningful knowledge bases tailored around their particular aspirations, skills or aptitudes. As we have seen, the increasing marketization of universities discourages this from happening somewhat with its focus on competition, production and efficiency. As Anton, referring to the great philosopher Immanuel Kant, identifies, 'he spent most of his career on pondering things rather than producing paper after paper' (Anton, p4). Lilly too longs for a culture of slow scholarship in the academy, asserting that this would surely encourage academics to publish more meaningful work. 'Sometimes when I read publications of people and I think they just publish for the sake of publishing, you know...the pressure of publishing...' (Lilly, p15). Heather also laments the need to publish to rigid standards, irrespective of the realities of the life of the author. As previously noted, Djodjo, who also works in the academy, wishes there were more room to 'explore my potential'. This shows that the rigid standards of neoliberal education apply not just to the students, but to university staff as well.

Ava states that the goals of education should be centred around

...developing a culture of interdependence, collective accountability where we recognise each of us has value and knowledge... instilling a sense of humanising liberation within each student, faculty, staff and administrators. This social component is missing from much of the schooling experience.

Ava, p3.

This more holistic and integrated appreciation of the student may help to combat issues such as isolation. Both Christine and Patrice expressed concerns about education leaving certain students behind. Contemporary education seems to be conceived of as a journey, and you better get on that train or else you will fall between the tracks. It doesn't matter if some students haven't been able to make it to the train. There is no time for stragglers, we must get to the end point. Viewing every student as having 'value and knowledge', regardless of how they 'perform' academically, may be a step in the right direction for Ava's vision to be realised (Dolmage, 2017). But this would mean slowing down, taking more time, engaging with each

student to make them feel like their lives matter, and they are worthy. Shunuli talks about respecting other people's life journeys,

...recognising that everybody's learning and growing, that no we don't have to end up on the same page with the same opinion at the end of the day but we should be able to engage other people respecting where they're coming from and being aware of where we're coming from, those are skills that should be taught.

Shunuli, p58.

Shunuli is advancing the need for students to learn about the ways in which their own positionality affects how they relate to other people, and consequently be more mindful of this in engagements with others. This more rounded appreciation of the student's story fits well with other recommendations from Lilly in particular;

We just need more time for people, more compassion... more, because everyone expresses differently, everyone has different ways of thinking, different ways of understanding so we have to allow that opportunity for different people to do things differently and then there's no one way in our and to be honest with you if we don't do that I can't see anything changing really unless with compassion and embrace the diversity in a genuine genuine sense not superficial, not surface...

Lilly, p9

Lilly continues with her impassioned desire for an education system that appreciates diversity;

I think it should help children develop and grow up and to learn I think how to be human, how to be able to respond to each other, how to respect each other, how to value each other and that is the core core education really and I think okay you have different topics to cover but I think that is the core of education is great tolerance, acceptance, compassion.

Lilly, p9

Teaching children from a young age how to discuss difficult topics with respect; how to communicate using different modalities such as sign language; teaching them Braille; teaching about different religions, different ethnicities, and different sexual preferences would, as Lilly, Abdu and Ava identify, help to create a culture of tolerance and acceptance. Embedding this in the curriculum, perhaps alongside the 'core' subjects of Maths, English and science, would ensure that these qualities were inculcated into society (Johnson & McRuer, 2014). This is not an attempt to flatten out differences by normalising them. Rather it is an attempt to make non-disabled people realise that there are other paths, other ways of living and being that embrace more egalitarian, relational modes of existence (Mitchell & Snyder, 2015; Dolmage, 2017).

Shunuli felt that the goals of education ought to be centred around providing students with the tools, support and guidance to ‘accomplish and do whatever it is they would like to do, because in an ideal world education is not about ensuring production but rather is about recognising and affirming human value and allowing people to enhance what they already have’ (p43). This can be said to be an important distinction of access to an essential area of social life that the Social Model appears to be lacking in its delivery. Access to an education that is based around the competencies and desires of the student, according to reports from Heather, is a privilege accorded to the non-disabled. In this light, academic success would be defined as the student meeting the individual goal that they set for themselves and/or making concrete step towards it (Mitchell & Snyder, 2015). In my opinion, this would incorporate the eradication of the gatekeeping of education; the removal of filtering access to further education with the stipulation of passing core subjects. This reflects Ava’s vision of academic measurement; she reflects that the term measurement should be modified to ‘progress’ in order to reflect more accurately the advancement towards the personal goals identified by the student. She states, ‘it’s more about collaboration or making room for such collaboration’ (Ava, p5). In this way, the student takes an element of control over their own instruction.

Lilly agrees with this conception of ability and success being measured on more personal terms. When asked how she would define ability, after contemplating the question for many minutes, she muses,

Ability. (Pause) (Laughs) (Long pause). It’s a really good question (laughter) I think to me it probably means to be able to, to be able to, erm, convey a message really, you know, and be able to raise awareness not educate but help people learn about certain things.

Lilly, p11

Defining ability in this way means that she is highly successful, as the author of books, chapters and journal articles ‘raising awareness’ of disability issues. This is a very personal definition formed through her individual version of what ‘being able’ means. It is this personalisation Studies in Ableism focuses attention on: by contemplating what ‘ability’ and ‘success’ would look like to her, Lilly is able to find a sense of fulfilment in her own terms. This would be the kinds of values I feel education should foster. It would entail a commitment to questioning and unpacking the concept of ‘ability’ (Wolbring, 2010; Goodley, 2014; Campbell, 2008). This would entail lecturers forming bonds with students, and so would necessitate smaller class

sizes. It would be difficult to achieve, but perhaps this is something that universities could work towards.

Lilly reflects,

I think my views are not less than everybody but I think if you made education inclusive, i.e. if you provide say a different form of handouts or different form of books, you know, so it can cater for different kind of impairments automatically so then don't need to make extra adjustments for students as such. And just so that we make education, er, reflect responses to different needs so that there's no need for any adjustments, every child feels valued and included. And I think some things, contrary to what people believe, doesn't need a lot of funding and a lot of adjustments, it just needs slight attention and attitude to their way of thinking, you know. And it's a very utopian idea and we're very far away from it but if we work towards that...

Lilly, p 24

Speaking personally, I fail to see why this is a 'utopian idea'. If schools and universities were properly, fairly funded this could be a reality. This view of education, as supportive and inclusive, may serve to widen the participation of disabled students in academia. As Heather notes;

Exposure to the academy is the important thing. Disabled people just being present changes it and the exposure... because it forces the academy to rethink what it's doing, to rethink what is natural much in the same way as the presence of women changed the academy or the presence of LGBT community changed the academy or is changing the academy because there is a long way to go.

Heather, p 35

Forcing the academy to re-think what is natural would undeniably be a significant move. As Goodley (2014:104) recognises, 'The presence of disability provokes a reconsideration of ableist education. Education's obsessive relationship with academic standards and school performativity becomes destabilised or crippled by disability'. We need to unsettle the archaic thinking undergirding the ideology of tertiary education, and question the values we want to instil in our students. By making education more inclusive and accessible we would learn from the people that have been traditionally excluded from it. As Anton recognises,

...we would enable more people to not only succeed in academia but access it, the wealth of knowledge that we produce and we could equally learn from those people who either don't have access to academia because of the current definition of academic success, or not even thinking about accessing academia because they don't like how academic success is defined.

Anton, p2 (transcript 2)

Perhaps the most radical and fundamentally appropriate suggestion garnered from my participants is one from Abdu;

When you talk about inclusion, it's also like sort of dictated inclusion by assuming that the current situation is a principal and this one is an exception and we will try to include the exception by extending and fixing some problems. They have not tried the concept of reversing explanation.

What I'm saying, for example, like, for example, I know Braille right, meanwhile yeah that's good but because of those guys who are not reading the Braille and I am prepared to write on the computer, I can do that, but why don't they try to write Braille because they have also eyes, if you talk about impairment. I don't have my eyes, they have their eyes they can read Braille through their eyes, why don't they try it?

Abdu, p16&17

Why must it always be that way, that disabled students should try to squash themselves to fit the mould of non-disabled students? If disabled students are defined as incapable of achieving certain standards, why make it harder? In the same vein, if non-disabled students are so capable, why can't *they* be the ones to try to negotiate things like alternative methods of communication such as Braille? What value would be found if we approached education in this way? How would students respond if, from a young age, they were taught to value diversity? What if teamwork and collaboration were promoted instead of an incessant focus on competition and individual productivity? Disabled students are valuable, not least because their experiences may give light to other modes of existence. As Heather notes, 'I just wish the education system would wise up and recognise the richness of what it has there' (p56).

6.4 Discussion for Project One

The narratives of my participants allowed a rich, evocative account of disabled people's experiences within university education. This supported an exploration of my three key research questions;

- How is the neoliberal ableist agenda inculcated into university institutions?
- How does this impact upon the psycho-emotional well-being of disabled students?
- What alternatives could be conceived of for the future of education that goes beyond the neoliberal agenda?

I believe I have begun to stimulate possible responses to all three of these research objectives. As I stipulated in Chapter 1, I do not hope to give definitive, concrete solutions to these areas of concern but instead to generate conversations and contribute to the dialogue surrounding these important topics. Following the spirit of post-conventionalism, the modus operandi behind this thesis is to encourage all future readers and society as a whole to question hegemonic ideas and unsettle normative thinking. The ideal neoliberal student is independent, autonomous, self-directed and self-contained. Why? Who benefits from this description? What happens to the individual student who tries to emulate these ideals? Can these ideals be conceived of differently? What would happen in society if these attributes were modified? These are the areas that I hope you, the reader, will have begun to think about through reading this thesis.

The sorting of my raw data into themes has, I hope, provided the reader with a sense of direction. I explored 'belonging' first and foremost as I believe that it can be considered to be a profound platform for feelings of security and groundedness that we all need as human beings. For my participants, however, this sense of 'being at home' was often precarious and highly conditional. They felt, consciously and unconsciously, that they were under greater pressure to 'prove' themselves worthy. Sometimes this was in an effort to bestow gratitude for the support shown to them; sometimes it was driven through a fear that they would be 'sent back to special school', a fate where their future pursuits would be curbed. Other times this pressure was put on themselves; a driving force to emulate the (non-disabled) 'norm'. Narratives told of the poor prospects of disabled people, galvanised by negative stereotypes and the assumption that opportunities in life are severely limited for people with impairments. This ignites a feeling of psychic disequilibrium - a feeling that one belongs (within a certain group or place), and yet, one does not and cannot hope to belong anywhere. This is often caused by the narrow and restrictive reactions to disabled people, rather than by any impairments that they have. As we have seen, the environment of the university frequently conspires to make disabled students feel unwelcome, as evidenced by the vast majority of my participant's testimonies. This goes beyond physical access issues to note that the language used in many academic publications is restrictive, and the format that is used to habitually display evidence of knowledge production is bounded by narrow and normative ideals. The emotional labour of wanting, often desperately, to belong caused significant stress and hardship to my participants. The experiences of other Others was also suggested by my participant's narratives, and I have briefly explored the impact of racism, homophobia and adoption that were related to me in the

interviews. These stories exacerbated the feelings of disconnect, detachment and division that my participants felt.

Then we explored the effect of the lack of appropriate support and accommodations. There are legal requirements in most western countries designed to protect the rights of disabled people to an education. The language used in providing ‘accommodations’ and ‘reasonable adjustments’ is particularly pertinent. Reasonable to whom? If disabled people’s needs were taken into account at the forefront of pedagogical design, there would be no need for adjustment based on the presence of impairment. Accommodations are not designed for the disabled student to thrive, but instead to make the disability temporarily go away (Dolmage, 2017). Accommodations are not designed to ensure that courses are accessible, but to retrofit those students that have signalled that they cannot cope with the course requirements as they are presently stipulated.

Numerous participants’ narratives highlighted the burden of self-advocacy, and many of them stated that this added obligation caused them to be physically and emotionally sick. Disabled students are forced to outline their weaknesses, which are construed as deficiencies in need of repair and correction by the recruitment of non-disabled others. This reinforces the power imbalance between the kindly universities who may or may not bestow adjustments to the individual student who is deemed as having innate and blatant inadequacies. This serves to emphasise the conclusion that disabled students do not belong in universities. The pressures involved with the increasing marketization of universities (Molesworth et al., 2011) leads lecturers and staff to concentrate their efforts more on the Super Samanthas, leaving other students to fall by the wayside (Natale & Doran, 2012). This has led some of my participants to endeavour to emulate the ideal non-disabled student. They felt like they had to morph able-bodiedness in order for their existence at university to be tolerated.

This phenomenon of morphing able-bodiedness had a significant effect on the psycho-emotional well-being of my participants. Several of my participants have absorbed negative cultural messages about disability (and therefore themselves) and they use these images to reinjure themselves every day (Mason, 1992). I am including myself in this category. No amount of social legislation will remove the feeling that I am inherently less worthy than my able-bodied counterparts. The infiltration of neoliberal ableist ideals that have seeped into the mind-set of my respondents has a significant impact upon their self-esteem and self-value. Through internalising beliefs and ideals that devalue disability, my participants were frequently

caught in a conundrum of perplexity. This led to a disavowal of disability, causing inner conflict and disengagement with adopting a disabled identity. Seepage of neoliberal ableist ideals into the university and onto disabled students is often covert and imperceptible, but as this study has shown, it has powerful effects on disabled students.

We proceeded to explore some more positive experiences of university that my participants narrated. In a few cases university staff were shown to be more flexible and empathic in their approach to the disabled students in their cohort. This was evidenced by a greater degree of compassion and understanding in their reported relations with the students, which provided relief to them. Many of my participants suggested smaller class sizes and less time pressure would aid their educational experiences. A number of my participants do or are beginning to hold themselves to different standards; ones that embrace interdependence, relationality, connectivity and integration. I showed how some of my participants were starting to reject the impositions inflicted on them by the strangulation of neoliberal ableist ideals.

6.5 Conditional neoliberal inclusionism

Accommodations, it can be argued, provide and promote a form of neoliberal inclusionism. ‘You too can be part of us’ they say, ‘but you have to be willing to admit that by your very embodiment, you are faulty. But do not despair! We will find solutions for you. You can become part of our team!’ The narratives of my participants in this study perceptibly longed for another way; *not* to be taken under the benevolent wing of conditional neoliberal inclusionism, but instead to create their own team, make up their own rules and play the game of life on their own terms. Instead of conforming to internalised scripts that devalue their existence, my participants are beginning to see that there are a vast array of ways of living generated by ‘the active transformation of life that the alternative corporealities of disability creatively entail’ (Mitchell & Snyder, 2015:2). My participants live their educational lives as openly *interdependent*, and this can be construed not as a form of oppression, but instead as a more meaningful desire to incorporate relationality and connection into the fabric of our collective genealogy. The methods of working together that disability entails may provide ways in which we can learn to live collectively as a society, not in suspicious competition with each other. My participant’s narratives have shown that they want a different world, one that is not restrained by the strangulation of neoliberal ableist ideals and ruled by market forces. Shildrick (2009) notes that disabled people are making tremendous strides into securing the rights

afforded to non-disabled citizens, yet warns that with these come the obligations and expectations of normative citizenship. The question disabled people have to ask themselves is, 'do we want to live by these rules?' As Mitchel and Snyder (2015:7) espouse, disability viewed in this way 'functions as a disruptive force of resistance in sedimented systems of privilege accorded to normative bodies within nationalist imaginaries of ableism'. This is not to deny the oppressive realities of occupying subordinate social positions, but instead to incorporate the actuality of vulnerability and sensitivity as positive experiences that bring an appreciation of the complexity and richness of human life. This is a *productive failure* to adhere to the unrealisable projects of neoliberal ableist education. In providing accommodations and adjustments to the instruction techniques in tertiary education, it can be argued that we are witnessing ingenious practices of normalisation, hidden under the guise of increasing access. The insinuation is that disability needs to be propped up, to be given special consideration to be brought up to the (indisputably higher) level of the non-disabled and therefore to level the playing field. There is no question of the dominance of able-bodiedness in this process of neoliberal inclusionism, nor of the possibilities and potentialities of disability.

The marketization of education should lead us to question the purpose of education; is it to create and pursue knowledge, or is it to regurgitate doctrines sedimented into the fabric of everyday life? Is it to formulate new modes of existence that are desperately needed in today's crumbling world, or to continue to promote antiquated, tired ideals of self-centred individualism? As Mitchell & Snyder (2015:22) implore, we need to 'reimagine ways of artfully living less productive, less consumptive and less exploitative lives'. This has particular applicability to the world of today, with environmental concerns specifically and with the threat of war looming on our horizons.

As Goodley (2014:104) perceptively notes, the very presence of disability in educational institutions:

demands humility on the part of educators in terms of what they are trying to achieve in educational settings...Pedagogies are found lacking and educational settings are found to be horribly instrumental. Disability exposes the failings of educational institutions that still, after years of disability advocacy and activism, fail to anticipate their responsibilities to a wide body of students and to the varied bodies of individual learners.

Goodley (2014:104) lists two of the most salient disruptions of the presence of disability in education that have been echoed in my study: firstly, that it disrupts the image of the ideal

student; and secondly that it destabilises the actions of educators. This destabilisation is radical, powerful and productive.

We must pay attention to the experiences of disabled students in academia, not only to reduce systems of oppression and discrimination but also to question the very values and doctrines held deeply within societies' collective genealogy that contributed to their oppression. A *Studies in Ableism* (SiA, Campbell, 2009) lens can aid in the interrogation of this phenomenon. Critically evaluating the neoliberal ableist regimes in university institutions can lead to the formulation of new ways of being. Disabled people must pay heed to Shildrick's warning of being subsumed, gratefully, into the realm of normative citizenship with its obligations and expectations. We have much to learn from the experiences of disability and disability is indeed a productive force in that it forces the academy to rethink what is natural, rethink the methods of instruction, and rethink the values it wishes to inculcate into its students. Conventional inclusion - or, what I would call conditional inclusion - is dangerous because it risks obliterating the distinct perspectives that disabled students have. We need to harness and include rather than dismantle the workings of power that marginalise certain forms of knowledge. Engaging with the values that my participants talked about would mean a complete overhaul of the education system. Less focus on productivity and sole-scholarship coupled with an increase in time spent contemplating concepts and ideas may prove to be beneficial to society as a whole. The insights of this project and the alternative value systems my participants described should be seen as viable alternatives to the workings of self-centred ableist neoliberalism.

SECTION 3: PROJECT TWO

MOTHER LIKE NO OTHER

CHAPTER SEVEN: THE BIRTH OF PROJECT TWO

MOTHER LIKE NO OTHER: EXPLORATIONS INTO THE ABLEISM INHERENT WITHIN MOTHERHOOD

7.1 Overview

In this project, I will be endeavouring to conduct a critical reading of the psychological literature on mothering – and their impact on mothering ideology – from a Studies in Ableism and a critical social psychoanalytic perspective *and* in the light of my autoethnography. This will make use of my position as an insider-researcher to give context and depth to this project. I will be analysing academic texts; online resources related to mothering; parental ‘guide books’; popular literature and advertising images in an effort to emphasise the predilection for dysconscious ableism permeating the lives of disabled mothers. This project will consider pregnancy, childbirth and early motherhood and the ableism that undermines these states for disabled women.

The ideal mother is created in an able-bodied and able-minded image, whose capacities are limitless. The principles that often inform this idealised image are so difficult to argue with that I am scarcely able to see the ableism bound up in this inception. I recently saw a blog post which contained a Facebook post by someone called Bunmi Laditan, about the strains of motherhood in recent times. It said:

How to be a mom in 2017: make sure your children’s academic, emotional, psychological, mental, spiritual, physical, nutritional and social needs are met while being careful not to overstimulate, under stimulate, improperly medicate, helicopter or neglect them in a screen-free, processed foods-free, GMO-free, negative-energy-free, plastic-free, body positive, socially conscious, egalitarian but also authoritative, nurturing but also fostering of independence, gentle but not overly permissive, pesticide-free two-story, multilingual home preferably in a cul-de-sac with a back yard and 1.5 siblings spaced at least 2 years apart for proper development but also don’t forget the coconut oil... How to be a mom in literally every other generation before ours: feed them sometimes. This is why we’re crazy.

(Gapasin Gnas, 2020)

This tongue-in-cheek (and blatantly sanest) perspective rings true for many people. The added pressure of social media and other internet outlets helps to create a feeling of anxiety, of never quite being good enough – for most mothers. It is entirely possible for disabled women to fulfil the vast majority of the expectations set out here, but the emotional labour of aspiring to do this, whilst under the societal insinuation that it cannot and/or should not be done, adds to the

strain of the role. The ableist element of this is that these expectations do not allow for fluctuations in energy levels; do not allow for mobility differences; and do not allow for comprehension troubles.

The paucity of help available to disabled mothers (Thomas, 1997a, 1997b; Grue & Laerum, 2002; Malacrida, 2008, 2009; Walsh-Gallagher et al., 2012; Prilleltensky, 2003; O'Toole, 2002; O'Toole & D'aoust, 2000; Lappeltainen et al., 2017; Parchomuik, 2014) shows the bigotry and prejudice that society holds towards us. Where there is help available, the vast majority of it is for wheelchair users, showing (I believe) a lack of imagination and a wearisome lack of awareness of other disabilities. There was only one website that I found to be useful for one-handed parents (info@disabledparent.org.uk) where I could pay to download a leaflet of practical advice on how to cope. This is from one of the rare organisations that is specifically designed for disability, pregnancy and parenthood, and the leaflet is entitled: 'One-handed parenting: a practical guide for new parents'.

My aim with Project Two is to tease out the ableism entrenched in the ideology and values associated with parenting and motherhood particularly. I hope that this work will contribute in new and divergent ways to the field of study. I plan to weave theoretical arguments in and around autobiographical narratives, using excerpts from existing literature to punctuate, illustrate and/ or diversify from my assertions. I want to question what we mean by 'motherhood'; what that entails; and interrogate the symbol of the 'ideal' mother. How do the twines of ableism permeate into this concept? Who benefits from this creation? What can be done to alter this view to incorporate and celebrate disabled mothers? I am aiming to address, if not answer, these questions in Project Two.

There is a stereotypical view that disabled women cannot and should not become mothers (Lappeltainen, 2017; Lawler et al., 2015; Lewiecki-Wilson, & Cellio, 2011; Lipson & Rogers, 2000; Malacrida, 2009; Lupton, 2012; Morris, 1989; O'Toole, 2002; Thomas, 1997), resulting in the critical gaze incessantly directed at those of us who do, and the lack of provision for mothers with bodies that do not conform to idealised standards. Social psychoanalytic theories have been used to a great extent by child development experts, albeit cloaked under the veil of normalcy. I will expand in the following chapters as to the extent with which social psychoanalysis can be used to shed light on, but also be implicated in, the perpetuation of an ideology that is conservative, limiting and oppressive in its views towards women, and the mothering capabilities of disabled women in particular. This will be used in conjunction with

a postconventionalist approach. This, I hope, will reveal the productive possibilities that disabled mothering brings, highlighting the insight that being ‘on the outside’ offers to a nuanced analysis of the different ways in which mothering can be performed. In this way, applying a postconventionalist lens to this issue contributes towards an expansion of a range of mothering practices that take into account variances of embodiment. Solely focusing on a SiA and a critical social psychoanalytic analysis would, I fear, feed into the construction of disability as oppression, as a cross to bear. This may enhance the imagined separation of ‘us’ and ‘them’, and give little possibility for envisioning the potentialities of disabled mothering. Bringing forth ideas of, for example, how to cope with a baby when one has fluctuating energy levels or how to change a baby with one hand are prime examples of the know-how that disabled mothers may have, and these are significant skills that need to be valued. I feel that the invigorating and disruptive inclinations of postconventionalist thought will enliven possibilities for the valuing of disabled citizens. It is for this reason that I have embarked on this separate study, inviting the reader to journey with me on my entry into the sacred hallow of motherhood.

The following three chapters will explore the ableism inherent within dominant perceptions of motherhood. This chapter will outline the premise for the project; the research questions I hope to address; and detail the methods I will be using to enable this process. Chapter Eight will ruminate on the medicalisation of child birth and child rearing, exacerbating the ableist capacities of governmentality (Foucault, 1997). In Chapter Nine I will be using a critical social psychoanalytical approach to focus on child development theories and their implication for mothering. In Chapter Ten I will begin to evaluate the potential of disabled mothers to slowly but steadily chisel away at the practices of ableism in motherhood, and outline the importance of this chiselling to society as a whole.

7.2 Debilitating Expectations

We weren’t expecting her to blaze into our lives for another ten days, but I felt the unmistakable surges of labour on the 11th of August 2016. Through the night I huffed and puffed, a searing twenty-two hours and then there she came, this tiny being that I didn’t know how the hell to deal with. The nurse handed her to me, and I tried to hold on to her throughout the ‘after birth procedure’. I tried to nurse her through the excruciating pummelling but after half an hour I had to give her to my husband to hold. I wish that I had been able to hold on to her, and the terrible guilt I feel at not creating the precious mother-child bond at this crucial time will never relinquish its grasp on me. Nor will the fact that, in place of the immediate utter love I had been lead to believe I would feel for my child was feeling of terror-induced anxiety. The fact that this love

came almost immediately afterward is neither here nor there; the fact is that my primary thoughts were of me, not her and that is unforgivable. This is my terrible secret.

(Taken from my field notes, 'The diary of a Crap Mum').

It is interesting to note that I have never expressed this to anyone, not even my own mother. I do, by the way, feel overwhelming love for my incredible child, and I would give my life for her a thousand times over. But it is the narrow and coercive nature of compulsory able-bodied mothering that my questions arise from. The ideology of motherhood is seductive in its tender biddings, in its presumed innocence. The guilt that accompanies any alleged wrongdoing is borne out of layer upon layer of hegemonic social 'truths' that are damaging to all women (Douglas & Michaels, 2004). What follows, hence, is an attempt to uncover the deep social discourses around motherhood and probe the ableism lurking within it. The debates around the ideology of motherhood are not new; nor are the calls of disabled women to be included in the composition of mothering. What I am trying to probe are the nuances that create disability disavowal by 'outing' the 'able' - by articulating the values embedded deeply in the ideology of motherhood. I define mothers here as anyone who engages in the act of mothering - not solely biological mothers, but adoptive mothers, grandmothers, relatives, step-parents, and fathers. The common assumption, though, is that this person is the biological mother, and I shall refer to 'the mother' from here on. The mother-child relationship is deemed to be sacrosanct - unique and irreplaceable. It is a commonly held belief that any failures in the psycho-emotional well-being of the child can be attributable to the success or failure of this relationship and the hallowed bond that surrounds it. The exact nature of mothering tasks is historically and culturally specific, but there is one aspect that is common to all societies, and that is its ties to gender (Windebank, 1996). There is an incessant focus on the child's early years and the formative relationship of the mother-child bond. It is therefore deemed crucial that the mother 'gets it right'. No alterations or allowances are made for instances of the mother having more than one child, for example, or for the particular circumstances and social position of the mother and child in the first place. The welfare of the child is assumed to be the primary responsibility of the mother (Windebank, 1996) and therefore she must invest all of her energy into providing and maintaining the highest quality of care, preferably unaided. To admit to needing help identifies the mother as unfit in some way, as unprepared and incapable. Dominant ideologies of motherhood in the western world are deeply rooted in assumptions of biological determinism; '(b)ecause of the seemingly natural connection between women's childbearing and lactation capacities and their responsibility for child care, and because humans

need extended care in childhood, women's mothering has been taken for granted' (Chodorow, 1978:3). Hence women's role in the rearing of children is rarely analysed in ways that do not pathologise mothers. This ideology encompasses a presumption of all things women are stereotypically considered to hold dear; the ultimate manifestation of the ability to demonstrate care and nurture – apparently the epitome of femininity. This sentiment has been at the forefront of much feminist discourse. However, the lives of many *disabled* women complicate this issue further because of the prosaic and clichéd depictions of disabled women as being asexual, dependent and therefore unequivocally unsuited to the role of motherhood, in its dominant narrative. This shifts the boundaries somewhat of the traditional debate about women's choice in becoming mothers to incorporate a wider social policing on reproductive liberty.

Expectations around mothering are implicit and, as this study will show, ableist (at least in the global north). This is most clearly shown in the censure of certain groups of mothers, with some being given free rein to mother as they see fit (as their social status grants them invisibility) whereas others are placed under public scrutiny, effectively or in some cases literally policed by public bodies and governmental control. Childcare and child rearing practices are relegated to the private sphere, robbing families, particularly mothers, of the ability to relate their private 'troubles' to wider public issues (see C. Wright Mills in *The Sociological Imagination*, 1959), a point which I will be expanding upon in Chapters Eight and Nine. Issues that arise in parenting, as we will explore, are seen to be the fault of the individual – and mostly the individual mother. I will attempt to address the following research questions in this study in order to tease out the manifestations of ableism in motherhood.

7.3 Research questions

- What is it specifically that is valued in motherhood, and in what ways are these values ableist?
- How do we as a society uphold and reinforce these values?
- How can the study of ableism, in conjunction with a social psychoanalytical and post conventionalist approach, be used first to expose then to challenge and break down these stifling structures in order to forge a path for more creative mothering practices?

These chapters will attempt to navigate the myths surrounding the ideology of mothering, briefly tracing the possible origins through the postulations of psychoanalysts such as Freud, Klein, Bowlby and Winnicott (ableism's production), to the cultural scripts and growing medicalisation and psychologisation of childbirth and childrearing in Western societies

(ableism's performance). There have been various attempts at challenges to these master narratives, especially from authors in the race and ethnic relations and queer studies fields, but the notion of 'disability' rarely features as a viable and worthy provocation to the prevailing script. In Chapter Ten I explore some of the ways that disability could potentially disrupt the ableism inherent within normative conceptions of motherhood (ableism's demise).

7.4 Research Methods: Autoethnography and Theoretical Literature Review

In the following section I will outline and justify the methodological approaches I used to 'out' the 'able' (Campbell, 2008) in Project Two.

7.4a Autoethnography as a research method

The potential benefits of an autoethnographic approach are that it offers a unique way of expressing innermost thoughts, feelings and perceptions that provide insight into the complex relationship between the psyche and society. Allowing validation of personal stories is essential as they form part of who we are; how we feel about ourselves and how we relate to others. Furthermore, the expression of feelings of self-blame and failure has ties to the representation of disability as individual, and thus it speaks in response to narrow conceptualisations of mothering and advances wider societal issues. This is crucial to address my research questions. The use of autobiographical data here will indicate how I as a disabled mother position myself within society, and how society shapes and frames my self-concept.

The danger, however, is by expressing feelings of incapacity and vulnerability, this will reinforce the negative representation of disability that we are trying so intensely to re-imagine, unintentionally reproducing societal stereotypes of disability (Mogendorff, 2013). This is what I term the 'freak show' dilemma – by exposing ourselves to the critique of the academic world through expressing intimate, poignant details of our personal lives, we are in danger of inviting the vultures to peck away at will on our very souls. It seems to encourage a voyeuristic fascination with differential embodiment, the distasteful enchantment with the 'other': 'how *does* she manage? Poor thing...' This can be a profoundly frightening prospect for many researchers, and they may choose not to disclose their personal relationship to disability for fear of reconfirming personal, singular responsibility for disability instead of reframing it as the cultural signifier that it is. But by not allowing these things to be discussed, it shuts off and closes down part of the disability experience, silencing us, making our particular knowledge invalid, unacceptable, and unworthy (Watermeyer, 2013).

A possible response to this would be the careful execution of reflexive, politicised, contextualised autoethnography that addresses the broader social issues at play. I combine this with an evocative narrative style that ‘fractures the boundaries that normally separate social sciences from literature’ (Ellis & Bochner, 2000:744). My hope in doing this is to invite compassion and empathy, and ultimately to ‘connect the practices of social science with the living of life’ (Ellis, 1999:699). As a response to the negative portrayals of the ‘worthiness’ of autoethnography, I wish to relate a quote taken from an article written by Ellis, Adams & Bochner (2011:283):

Autoethnography, as a method, attempts to disrupt the binary of science and art. Autoethnographers believe research can be rigorous, theoretical, analytical and emotional, therapeutic and inclusive of personal and social phenomena... {they} view research and writing as socially just acts; rather than a preoccupation with accuracy, the goal is to produce analytical, accessible texts that change us and the world we live in for the better.

This is what I hope I have produced.

In the following chapters, the reader will be furnished with a rich understanding of my inner world, illuminating issues that otherwise may not occur to them. But why, though, is it important for the reader to be able to see things from my perspective? There are various reasons that I want the reader to be privy to my thoughts: firstly, this is a way of intimately displaying how I, as a disabled mother, interact with others in my socio-cultural context, and the impact that these interactions has had on me. This is one way in which I can show the psycho-emotional consequences of ableism in action. Secondly, through this method I will aim to highlight the impact of social forces (such as the neoliberal focus on marketization and the exclusion of disability within those markets) and the effect this has had on my lived experience. Finally, narratives often have incredible evocative power - to draw in and mesmerise, or to repel and disgust. Some of the stories that follow may have the reader reacting in such ways and some won't, depending on the life experiences of the particular reader. I have tried to use a critical approach to my autoethnography; not to be critical of the actual story, but to approach it with a view to uncover what that story can tell me about myself, about society, and about the tacit manner in which these interactions can pass by unnoticed unless they are emphasised and made to be interrogated. In this way, through my use of autoethnographic material I seek to expand the understanding of social phenomena by relating my experience to the broader social reality of ableism and offering a contextualised critique of ableism in action. This research method has, at times, made me intensely vulnerable, prone to tears, anger and sadness – but in

these times it has also proved to be therapeutic and transformative. Armed with the tools of theory, it has made me see how the events that shaped me in a negative way still have the power to be transformed into something that *gives* energy instead of draining it away. This power can then be harnessed to reveal the productive possibilities of disabled mothering.

The change in my ontological processes as a mother is startling, so much so that it is difficult for me to remember my life before my daughter was in it, and to remember how my life had any purpose to it. That is not to say that the only reason to exist is to have children, and childless individuals therefore have no purpose; not at all, but for me having this wonderful person in my world has had a profound effect on my views, my wants, needs and desires, and my overall perception of myself as a worthy human being. This ‘worthiness’, however, is decidedly precarious and unstable, and fluctuates dramatically over the course of each and every day. This tenuous sense of worthiness is linked to societal pressures and perceptions of being disabled on one hand, and being a mother on the other, and the intersections of these two identities. I feel that my present experiences of trying to negotiate these normatively oppositional identities has further strengthened my critical positionality. Theory has been a powerful tool with which I can think through the ideology of mothering. Being on the outside looking in, I can use my particular vantage point to unravel the complexity of threads that make up the entrenched social perceptions of what it means to be a mother, revealing the rotten core of neoliberal capitalist values at its root. Through this, we can begin to challenge and refuse such limiting concepts.

7.4b Theoretical literature review

I applied the awareness gained from my autoethnographical data in conjunction with other similar published narratives in the field of disabled mothering. This was an attempt to draw out and consider what the existing literature tells us about the present situation of disabled mothering, and to propose some tentative ways forward. I used this form of exploratory literature review in order to select, summarise and analyse the breadth of literature available on mothering, mothering ideology, intensive mothering and disabled mothering. This was then used to focus the specific research questions that, in my opinion, remain unanswered by these studies. These questions are related to the exclusionary reverence of motherhood and to what extent this precarious approval is ableist.

7.5 Search terms

In order to do this, I employed a wide range of search terms in order to try to capture the slippery but enduring nature of ableism. The terms that I searched under included mothering; motherhood; ideal mother; ideology of mothering/motherhood; ableism; disability and motherhood/mothering, disabled parent, ableism and mothering/motherhood/parenting; ableism in motherhood/mothering/parenting and parental rights (which I have barely touched upon as there are many other studies that investigate the rights-based issue of disability and parenting). I have consciously omitted sources from majority world contexts, as I wanted to focus on mothering in the western world. This, of course, would be a fruitful area for future research.

This study would also benefit greatly from an investigation into the ableism inherent within hegemonic social perceptions of mental illness and mothering, but this study focuses heavily on physical disabilities. I admit to being subjective in the fact that I was looking for early mothering experiences, partly to tie in with my autoethnographical data, and so have consciously discounted sources that discussed the experiences of mothering older or adolescent children. I have also drawn partly from news reports, social media, popular literature and personal blogs in order to provide a more rounded picture of Western society than focussing solely on academic theorisations. My search criteria belies my position, and possibly researchers who have a different background and ontological experience will perceive the issue through a completely different lens. I don't want to escape my ontological position as I feel that being physically disabled and being a mother gives me a particular knowledge, a particular insight into the understanding of disabled mothering. Nevertheless, I acknowledge that my experience cannot be generalised; it is the outcome of distinct occurrences in relation to exposure to distinct situations, and therefore my reality will deviate in important and considerable ways from other peoples. I acknowledge that I am writing from a relatively privileged position, with my 'safe haven' nuclear family in a low-to-moderate economic dispensation. What I wish to draw attention to is the themes and ideas that I will identify over the course of these chapters that *are* applicable to many disabled mothers in western society.

7.6 Theoretical tools

As I have detailed at length in Chapter One, ('Epistemological, ontological and theoretical orientations), my analysis will rest on a series of methodological perspectives that are informed by my ontology. This will also incorporate my new ontology as a disabled mother in an ableist world. Therefore the analysis will be based on a broad constructionist approach to genealogies

of knowledge informing and reproducing society's norms and values, which are then consciously and unconsciously absorbed, integrated, internalised or rejected. In other words, this theoretical orientation adheres to the idea that knowledge is socially constructed, and learning is an active process of knowledge construction. This will draw on social psychoanalytical theories to show how disabled mothers subvert dominant constructions of disability, producing a 'lack of support of the lack' (Wilton, 2003:381). If disabled women are 'able' to 'do' motherhood, where does this leave the imaginary line between 'abled' and 'disabled'? It will show, also, how social psychoanalysis itself can be implicated in the 'reproduction of anxieties surrounding disabled bodies, and ableist culture more generally' (Wilton, 2003:372).

Although adhering to caution in the use of psychoanalysis to disability, and the overwhelming individualisation and pathologisation that can occur from the non-critical application of its theories, I believe with others (Goodley, 2006; 2011), Reeve (2002; 2014) Wilton (2003), and Watermeyer (2009; 2013) that a critical execution of it can be beneficial to the study of ableism. Social psychoanalytic ideas, says Goodley (2011), can be used in fruitful ways to enrich and make sense of the ways in which disabled people are made to feel like outsiders by society. In particular, they are useful to describe what Reeve (2008) terms the barriers 'in here' – barriers inside our self-perception that greatly affect our ontological being in the world. This perspective accentuates the creation of self in relation to others, and reflects the importance of the social self. There are numerous examples of when I retreated into myself through perceived attacks on my psyche. This powerfully relates to my autoethnographic data, and provides insights into how this data can be used to reflect wider social and cultural conflicts encountered by living as a disabled mother in a world so strongly dominated by neoliberal ableist values. I will make use of social psychoanalytic terms such as projection (where we ascribe to others that which we cannot face in ourselves); the unconscious (the processes of the mind that occur automatically and are not available to reflection); defence mechanisms (where we unconsciously seek to distance ourselves from unpleasant feelings – defence mechanisms can include denial, regression (where we retreat to an earlier stage of development in order to cope with overwhelming thoughts) or compensation (where we recognise a perceived lack in our skills but attempt to compensate for this lack by emphasising other skills (psychcentral.com). An example of this would be my zealous determination to breastfeed, as we shall explore later); repression (an unconscious need to push down or conveniently 'forget' unwanted feelings (Billing, 1999)) and introjection ('internalising desired aspects of the good life' (Goodley,

2011:722) in these chapters as I try to think through the processes of ableism. ‘Disability’, Watermeyer states, ‘awakens discomfiting feelings in all of us, potentially triggering defence mechanisms which distort perception and affect the way in which we respond, as societies, to people with impairments (Marks, 1999a; Watermeyer 2006)’ (Watermeyer, 2012:52). This can be used to shed light on the plethora of ways in which:

non-disabled people and disablist culture symbolise, characterise, construct, gaze at, project, split off, react, repress, and direct images of impairment and disability in ways that subjugate, and at times terrorise disabled people while upholding the precarious autonomy of non-disabled people.

(Goodley, 2012:181)

This perception is extremely valuable to the analysis of ableist society in relation to motherhood as it accentuates the complexity of emotions bound up in interactions with the non-disabled. Watermeyer, in his book *Towards a Contextual Psychology of Disablism* (2012) refocuses our attention on the psychological and emotional aspects of living in a disablist world, matters that are of crucial importance to this programme of research in particular. He argues, along with many others, that these aspects have been too long ignored in disability politics, but are fundamental to the ontological experience of many disabled people. Our relationship with (non-disabled) others affects who we can be, and in turn affects our psycho-emotional perceptions of ourselves. Psychoanalytical concepts can thus be used to name and describe the nuances of our interactions.

What I particularly want to uncover here are the *values* associated with mothering and to what extent these are ableist. (Readers are asked to look at Chapter Two for my understanding of ableism). In particular, I shall be interrogating the extent to which, by unproblematically adhering to dominant neoliberal principles underpinning the ideology of motherhood, we are unintentionally reinforcing the belief that only able-bodied, heterosexual, middle-class couples are capable of caring for their babies. A Studies in Ableism perspective will help me to do this. Allow me to reacquaint the reader with Goodley’s (2014:21) summation of ableism, as it has particular relevance to this argument:

Ableism’s psychological, social, economic, cultural character normatively privileges able-bodiedness; promotes smooth forms of personhood and smooth health; creates space fit for normative citizens; encourages an institutional bias towards autonomous, independent bodies; and lends support to economic and material dependence on neoliberal and hyper-capitalist forms of production.

This dense statement succinctly expresses the power of ableism to cloud and engulf the collective genealogy of society, reiterating the slyness with which it infiltrates thoughts and behaviour to insinuate that ablebodiedness is *of course* preferable to disability. This has particular ramifications to the arena of disabled mothering. If the very concept of a disabled mother is not recognised, then of course they are not provided for. The *disabled* mother is defined in relation to what she is (socially perceived) *not* to be. Not visible, not capable, not worthy. The assumption of autonomy and independence means that other, more *interdependent* and creative means of mothering are not given space to exist and flourish. The study of privilege and entitlement that can be gained from the peripheral view of the disabled sheds light on the overbearing and archaic value system that serves to constrain so many in this arena. The normative arrangements of social spaces and their restrictions has salience here from a SiA lens, which I will be expanding on in this piece. The project of ableism I aim to develop in this study is to unmask the values undergirding the ideology of motherhood (ableism's production) and to analyse how we as a society reinforce these values (ableism's performance). I will then (using postconventional theories) frame the ways in which disabled mothers potentially resist and challenge these normative notions.

We will begin with the trials and tribulations - and the medicalisation - of pregnancy, childbirth and early motherhood.

CHAPTER EIGHT: THE MEDICALISATION OF CHILDBIRTH AND CHILDREARING

8.1 Overview

We live with science: science surrounds us, invades our lives, and alters our perspective on the world. We see things from a scientific perspective, in that we use science to help us make sense of the world, regardless of whether or not that is an appropriate thing to do, and to legitimise the picture of the world that results from such investigations. (Erikson, 2005:224, in Faircloth, 2010:2)

This chapter will begin with an interrogation of the medicalisation of pregnancy and motherhood. This is not with a view to negate the valuable advances in *medicine* which have saved and prolonged countless lives, but to question the ethics in the appropriation of pregnancy and early motherhood from an ableist perspective. I will begin to probe the authority given to medical and scientific advice from experts in the early childhood years and expose the blatant disablism located within the practices of in-vitro screening. The promotion of perfected childhood, supported by adequate parental ‘choices’, will be expounded upon, fortified by the practices of ‘scientisation’ to give added plausibility to their claims. The assumption of a normatively working, non-disabled maternal body is rampant in the ideology of motherhood, resulting in the infuriating lack of provision for maternal bodies who do not conform to these standardised ideals. I will introduce the cultural phenomenon of biopower, and underscore the implications of this method of subversive government control for disabled mothers in particular. The ramifications of increased cultural authority given to medicalisation will, I hope, become clear as I begin to unravel the effect that medicalised language and the intrusion of sceptical practitioners can have on the psycho-emotional wellbeing of disabled mothers.

8.2 Childbirth

Women in the UK and other western countries have been shown that there are certain ways of preparing for childbirth that are ‘culturally appropriate, morally underpinned and socially acceptable’ (Miller, 2005:31). Pregnant women are expected to give their trust, and thus a large amount of their lives (and the life within them), over to the medical profession. This has significant concern for disabled women as this is a profession which has systematically and uniformly negated their bodies.

‘The act of birth is surrounded by all of the symbols of the medical profession and all that it stands for - science, power and knowledge’ (Henley-Einion, 2003:173). Medical terms and

references have been made legitimate in the birthing process, transforming a once social ritual, dominated by women, into a medical one dominated by men (Henley-Einion, 2003:181). The rule of patriarchy that was implied by the postulations of psychoanalysts that we briefly covered in the last chapter is demonstrated clearly here, with the insinuation that women's bodies are in and of themselves anomalous, prone to irrationality and emotion-induced behaviour. This appropriation sees women as fundamentally abnormal, as victims of their reproductive capacity and their hormones, and the entire pregnancy as a symptom of the intrinsically pathological nature of women (Cahill, 2001). The act of birth, patriarchy dictates, needs the management of men and the guidance of medical 'experts' to function properly, with pregnancy being treated as essentially a 'biological defect' (Cahill, 2001). Let's take a brief look at the history of how the birthing process was commandeered out of the hands of women and appropriated by men.

According to Cahill (2001), around the seventeenth century men began to challenge the traditional role of women in midwifery. It became more common for men to be present at the birth as medical professionals, assisting and directing the use of medical equipment such as forceps. Women, of course, were prevented from entering universities and training institutions because of their biological 'inferiority'. Furnished with their superior biological knowledge, the wisdom and insight of female midwives began to be unheeded and undervalued. This was furthered by the lack of training and regulation in the practice of midwifery. This has been used to indicate that 'scientific and factual knowledge is inherently `male', and therefore claim[s] supremacy over `female' intuitiveness, empathy and caring (Cahill, 2001:337). I am not denying the very positive impacts of *medicine* here, but trying to make the point that the dominance of medical and technical knowledge that dictate the *medicalisation* of pregnancy clouds the very real psychosocial effects of the transition from 'woman' to 'mother' which women could really benefit from. This points to a lack of appreciation of insight and experience which could be gained from a more feminist standpoint. The improvements in medical technology have led to more invasive monitoring of the pregnant body and the body within it, which we shall now examine.

8.3 A Critical Disability Studies approach to prenatal testing

Alongside advances in visual imaging technologies, the foetus itself has come to be aesthetically judged as 'viable' and 'healthy', or as defective. If the foetus has certain genetic markers, the pregnant woman will be brought back into existence and given the choice of an automatic termination. This is where the moral and ethical justifications for having an abortion

become simplified, and it is deemed legitimately justified to proceed with a termination if the baby's genes *aren't quite right*. The advances in PNT have positioned certain foetuses as being 'less worthy of the privileges of citizenship than other foetuses, and as liabilities to society' (Lupton, 2012:336). 'Prenatal tests', Saxton (2000:147) argues, 'have brought the revolution in molecular biology into the lives of ordinary people'. Such tests, once reserved for 'high-risk' pregnancies, are now carried out on a regular basis. The axiomatic decision to terminate if the foetus does carry the genetic markers of disability is in itself a disablist assumption. By relegating life with a disability to an automatically unwanted life and an invalid one, we can see that this smacks of disablism. If it is assumed that the foetus would have an unjustly difficult life if brought to term, argue disability rights activists, then surely the abolishment of discriminatory social *practices* should be the solution, not the elimination of disabled *people* (Saxton, 2000). The presumed need and desire to have prenatal testing points to the hegemonic perception that the life enjoyed by disabled people is inherently not as good, not as 'productive', or not as worthy of life enjoyed by non-disabled people. As Saxton (2000) asserts, it also assumes that raising a disabled child will necessarily be an unwanted burden on mothers. In this, there is no discussion of the potential joy, creativity or insight that disabled children may bring to this world. The whole issue of prenatal testing, it can be argued, underscores and predetermines future attitudes to disability in an intrinsically negative way. It conspires with the medical view of disability: that if there is a way to prevent it, then we as a society have a moral and ethical responsibility to do so. In making the argument against prenatal testing Adrienne Asch (2003) points out a number of misconceptions about life with a disability: firstly, that in subscribing life with an impairment to inherently unfavourable conditions, it fails to take into account the impact that discriminatory attitudes and social practices (which can be changed) have on this life; secondly, that it places 'unwarranted emphasis' (Asch, 2003:318) on the breadth of a person's opportunity range, rather than concentrating on the meaningful decisions that can be made within that range; and thirdly, that 'lacking' a 'capacity, skill or experience' (Asch, 2003:318) is fundamentally a bad thing. Rather, this 'lack' can and does lead to innovative and productive ways of being. This way of viewing disability - as intrinsically and unequivocally detrimental to one's life and one's opportunities - is constitutive of the narrow-minded, prejudiced medical model of disability, a model that most disabled people and their advocates are exasperated by. The problem with prenatal tests, Asch (2003) states, is that the identification of any impairments overrides and obliterates the very *being* of the potential child, and that this leaves no room to discover the other traits of this potential child.

Parsons & Asch (2003) point out, however, that the decision to terminate is often much harder and more complex than I have indicated. Indeed, they report that some disabled people themselves choose not to deliver a baby if the prenatal tests have shown it to have disabling conditions. Moreover, they remind us that the reasons for choosing abortion are often complex, and frequently have little to do with holding discriminatory attitudes towards disability. For example, families sometimes decide that they do not have the ability or the resources to provide for a disabled child, however much they would like to. I myself must admit to harbouring some reservations about my ability to cope with a disabled baby as well as Jasmine, despite my strong anti-ableist leanings. These reservations stem more from the lack of faith in my abilities as a mother than from wanting to discontinue the baby's life on the prediction of a disabling condition, but this highlights the complexities of the decision-making process where a termination is considered. Nevertheless, 'fear' - of disabling conditions, of the identification of anything other than the fallacy of 'normalcy' in the foetus - is abundant in the medical world, and has real psycho-social consequences for parents-to-be. Discourses of awe in the 'miracle of life' are conspicuous in their absence when disability is detected (Viol & de Waal, 2012). The forces of ableism are abundant here in the idea of 'perfecting' the child-to-be and, I will argue, continue throughout the life of the child from beyond the womb through the coercion on the maternal body of the bio-politics of pregnancy.

8.4 The ableist biopolitics of the pregnant body

Over time, the medical profession has succeeded in instilling a culture of fear around pregnancy and childbirth, enforcing increasing reliance on the 'expert' advice of doctors and other associated professionals. The myth that the hospital is the only safe choice for a woman in labour has well and truly taken root in European and American society. Along with this comes increased governance and scrutiny over the growing foetus. As Deborah Lupton (2012:329) observes,

The pregnant woman, by monitoring and regulating her own actions, is expected to create a shield of safety around her foetus by preventing any potentially polluting substances to pass into the uterus. Pregnant women are also expected to monitor their mental states, because the hormones associated with stress may affect their fetuses adversely, and to avoid certain spaces that may contain 'invisible lurking germs' (particularly difficult when a pregnant woman is also expected to attend regular prenatal checks in apparently germ-infested doctors' surgeries or hospitals as part of her health regimen).

This assignment of culpability will not ease once the baby is born; rather, the responsibility for the welfare of the infant, from the moment of conception, *always* rests on the mother's shoulders.

Pregnancy, once considered a natural state, has now come to be characterised in the western world in the language of 'risk'. The pregnant woman, thus, has lost her identity and autonomy as far as the foetus is concerned. The body of the pregnant woman itself is considered dangerously unstable and chaotic, with permeable boundaries, in a cultural milieu where static and bounded states are considered ideal (Lupton, 2012). The woman's previous identity as a woman with needs and wishes of her own is gone, replaced with her being solely a vessel for the unborn child. She no longer exists, other than to be highly monitored as a potential risk. The pregnant woman is portrayed as weak and irresponsibly influenced by her carnal desires, and so she must pay unyielding attention to the advice of the medical and psychological experts. This state of Foucauldian self-regulation is the epitome of biopolitics. Maternal responsibility and rationality here are intertwined, emphasising individual responsibility for risk management - thus denying or minimising state obligations. The discourse of the regulation of the pregnant body is infused with the notion (and expectation) of maternal love and selflessness. Mothering is considered too important to be left to 'the weaker sex', the 'damsel', the 'vacuous little women' themselves. Oh no. And far be it for the state to develop policies and practices to actually support mothering. Too expensive. Far better to blame the individual mother if it all goes wrong.

Nikolas Rose (2006) surmises that we are entering an era of 'perfected' human abledness, wherein we are experiencing 'a qualitative increase in our capacities to engineer our vitality, our development, our organs and our brains' (Rose, 2006:4). This molecular vision of life opens up serious debates around the kinds of societies we want to create, and who is given value within those societies. At the turn of the century, Rose (2006) states, the body itself came to occupy a prime site for the analysis of the clinical gaze. Through this shift in focus, the management of the body came to signify an opportunity for governments to regulate the health of its citizens, a process which Rose terms 'bio-power'. In his 2001 article, '*The politics of life itself*', Rose argues that the state has deflected its responsibilities for ensuring the health of its citizens, redirecting the responsibility to individual citizens themselves. This, Rose (2001) states, is capitalised upon by pharmaceutical companies and the leisure industry, and shapes the ways in which individuals think about their own freedom. Viewing health and responsibility in this way have dramatic implications for the arena of reproduction and the possibilities of

disabled mothering as it increasingly implies that mothering is a choice that should be exercised with caution, as the state cannot be morally relied upon to provide assistance in times of need.

The notion of biopower has led the authors Claus Ulrich-Viol and Ariane de Waal (2012:139) to state,

Nowadays pregnancy and birth, it seems, are impossible to experience without guidebooks... While obviously nonsensical with respect to their primary message – pregnancy and birth are known to have been accomplished ages before books, let alone guidebooks, were invented – such claims may be seen to contain a certain truth nonetheless: they express currently dominant forms of knowledge and/or beliefs about the two phenomena, lay down rules of conduct, define possibilities and responsibilities, exercise power and control. This way, they indeed play an essential role, if not in pregnancy and birth as such, then in constructing and maintaining a pregnancy and birth culture that today is heavily medicalised, secularised, and individualised.

Bio-power, Foucault (2009) argued, is a more covert, shrewd method governments use to control the population than the former methods of direct punishment. These operations were made as a preventative measure, in order to predict when aberrant behaviour would likely occur, to minimise the effects and stop them spreading (Viol & de Waal, 2012). In their article cleverly titled, 'Bio-power in societies of control: your essential guide to pregnancy and birth guides', these authors outline the systems of governmentality I have talked about here, including the different ways that governments try to cajole pregnant women into making the 'right' choices - for example, taking exercise, consuming healthy, nutritional food - regardless of their individual situations. This is yet more evidence of ableism – the assumption that the pregnant woman is able-bodied and that pregnancy and birth should be normative practices. The normalisation process doesn't end there; there are vast amounts of monitoring that occur in the name of ensuring the foetus' safety that the pregnant woman is culturally obligated to subject herself to. Additionally, the pregnancy and birth guides that these authors have analysed all succeed in propelling pregnant women back into the domestic sphere by highlighting the risks abound in the public sphere. This correlates with the de-politicisation of pregnancy, and prevents women from mobilising to be recognised in the public sphere. Women are advised, Viol & de Waal say, that they can only minimise the risk to their unborn baby by paying fastidious attention to continually updated advice from medical experts. The 2013 book, 'Your pregnancy, week by week' by Leslie Regan (a professor of obstetrics and gynaecology, it announces on the front cover) warns that 'it is impossible to eliminate risk from life, and pregnancy is no exception' (Regan, 2013:27). She goes on to warn us about the need to adopt

a healthy lifestyle in pregnancy; ‘Promise yourself that you will eat a well-balanced daily diet (see pp 43-49). Ideally avoid alcohol and keep caffeine intake to a minimum. If you are a cigarette smoker, stop today’ (Regan, 2013:27). Expectant mothers are strongly advised to protect their unborn child against ‘neural tube defects’ by taking a daily dose of folic acid. Most expectant mothers comply with this advice because they trust in the seemingly objective advice of experts, but the disablism is evident. By equating ‘defects’ with disability and the actions of an irresponsible mother, governments are again placing the fate of the unborn child directly onto the mothers shoulders, shifting the focus away from poverty and inequality. The high cost of some of these ‘recommended’ supplements is ignored, as is the relatively high cost of maintaining a healthy diet. In ‘The Wonder Weeks’, a book about how to monitor and optimise your baby’s (normative) developmental stages in order to ‘turn them into magical leaps forward’ (van de Rijt & Plooj, 2013: front cover), it perhaps inadvertently endorses stay-at-home mothering as this is seen as the best way to effectively monitor your baby’s signals. This is presented as being in the best interests of both babies and mothers; by being at home, constantly at the baby’s beck and call, mothers will ‘better understand the way your baby is thinking and why he acts as he does at certain times. You will be able to choose the right kind of help to give him and the right kind of environment to help him make the most of his development’ (van de Rijt & Plooj, 2013:3). This also assumes a certain level of cognition and awareness, and assumes that the environment that babies are in is always a matter of choice. In the case of disabled mothers-to-be, they are taught to rely on the postulations of professionals who have historically negated their lives. Disabled women’s inherent lives are imbued with the notion of ‘risk’ – just living a life with a disability is seen to be risky in itself. This is often intensified when a disabled woman is pregnant.

Through the side-lining and societal disengagement with disability issues, many experts do not know how to adequately treat pregnant disabled women. This leads some doctors to treat the pregnancy in an ‘alarmist way’ (Campion, 1995:136). The lack of appropriate access to, for example, examination tables and other perinatal facilities (Tarasoff, 2017) for some of these women enacts a substantial barrier to their care. As Frederick (2017:79) notes, the assumption that disabled women cannot or should not have babies, in conjunction with the project of normalcy, mean that the unique needs of disabled mothers are often rendered invisible. This misrecognition results in the market provision of products, goods and ‘expert’-driven advice manuals to be chronically underdeveloped for this population. The prizing of bio-medical normalcy (Frederick, 2017) and the deep-rooted devaluing of disabled existence mean that the

opportunity to access suitable products aimed at, for example, enhancing children's development is limited if the mother's embodiment differs from the 'norm'. Through the lens of ableism we can come to critique this failure.

The woman as mother-to-be is universalised, treated as a homogenous carrier, and her individual needs are not taken into account. This is where the ableist nature of pregnancy in neoliberal society asserts itself, masquerading as operating in the interests of the common good. It is assumed that all pregnant women that fit the idealised version are non-disabled and of 'sound mind', and if they are not it is assumed that they are deemed to present unnecessary risk to the life within them - a potential future neoliberal citizen. This cannot be allowed to happen. Non-idealised mothers, then, are increasingly not catered for. Ableism in pregnancy asserts itself in a myriad of ways; through the treatment of pregnant disabled women in medical settings, the search for anomalies in the foetus, to distrust in abilities as a mother, in some cases leading to disastrous consequences.

The all-pervasive monitoring of pregnant bodies, and the insinuation that good health can be assured through sheer will, if the mother-to-be is careful enough, points to a much wider phenomenon in neoliberal society: that good or bad health is indicative of vital elements in one's personality. Good health is seen as an embodiment of strong-will, self-mastery, and self-control.

A health that can be 'chosen', however, represents a somewhat different value than a health one simply enjoys or misses. It testifies to more than just a physical capacity; it is the visible sign of initiative, adaptability, balance and strength of will. In this sense, physical health has come to represent, for the neo-liberal individual who has 'chosen' it, an 'objective' witness to his or her suitability to function as a free and rational agent.

(Greco 1993:369-370, cited in Ruhl, 1999:111)

Ill health, then, is seen to be the embodiment of the opposite of the ideal neoliberal citizen, and the result of engaging in 'risky', irresponsible behaviour. Blame is placed on the individual, and the effects of, for example, poverty, are at best downplayed. Part of the magic of current western society is to blur the fine web of connections between the individual and society, and to obscure the position of mothering as always embedded within wider social relations. For example, as Kelly Fritsch (2017:245) notes,

(Disabled parents) face significant systemic barriers that often lead to social isolation. Not only do inaccessible playgrounds, parent-and-tot groups, and school buildings limit disabled parents, but disabled parents are also significantly constrained by poverty, inadequate and inaccessible housing, transportation and day-care... Systemic

ableism... contributes to increased social marginalisation and vulnerability, further opening up the disabled parent to negative judgements about their capacities to parent.

These factors are rarely taken into consideration when judging the skills (or apparent lack of skills) of a disabled mother. On a similar note, Claudia Malacrida (2007:479) identifies that 'normal spatial arrangements actively discourage parenting through their inaccessibility, and they also provide a more subtle message about the 'inappropriateness' of parenting with a disability'. If, as Foucault (1995) articulates, architecture suggests powerful indications of hegemonic ways of thinking, knowing and being, this offers evidence as to the invisibility of disabled mothers in society. Through the sometimes stealthy, sometimes explicit employment of biopolitics on pregnant women, they are highly encouraged to vet their actions through a process of stringent self-regulation, propelled by a plethora of 'expert' guidance. They are warned not to trust in the experiences of their own mothers or grandmothers, as 'expert' knowledge, don't you know, has moved on from then.

These observations merge smoothly with the promotion of neoliberal-ableism. As Goodley (2014:32) identifies, these ways of thinking about particular bodies gets 'under the skin, across the population'. Ableism, he notes, has become part of our unconscious collective genealogy, infecting our thoughts and actions – not necessarily in a mean-spirited way but as part of our hegemonic acceptance that 'this is the way things have to be'. The endless promotion of super-health and vitality (which the good neoliberal-capitalist citizen would utilise to increase productivity) has in its (not so subtly) hidden referent the disabled (read: incapable, unworthy) non-citizen (Goodley, 2014). Ableism has a way of offering valuable aspects of living as part of a community with one hand - access to social activities, transport, engagement with others etc. –but then taking them away with the other. This is what I mean when I refer to disabled people as non-citizens; that the benefits of societal living are diminished when they are not fully accessible to everyone. The advantages of citizenship are redirected to further endorse the privileges of able-bodiedness. Dysconscious ableism does this by infecting the thoughts of town planners, architects, and a dizzying array of others involved in the establishment of social institutions, *not* to include every form of embodiment when designing their social spaces. The insinuation contained in neoliberalism is that everybody has the same potential for success, but that some people fail (through personal lack) to achieve it. This is damaging, particularly in a society where 'one's sense of self and value are judged in terms of one's worth in the market economy' (Goodley, 2014:27). The ideology of neoliberal-ableism is neutralised in this assumption, and the prioritisation of non-disabled people is supremely naturalised.

But the most ingenious fact of this method of biopolitics is that pregnant women, along with others in their social milieu, are enlisted in the effort of self-regulation as a way to prove 'responsible' motherhood. Moreover, neoliberal society dictates that they *themselves* are responsible for the social environments in which they live! So insidious is the ableism around motherhood, and so sneaky is it of infiltrating our collective genealogy that we actually come to aspire to, nay even immortalise, normative forms of mothering - often without realising it.

Women are encouraged to make meticulous preparations for their unborn child, and I tried to do just that. I pondered and planned in careful and considered detail, purchasing the softest clothes and the latest gadgets; but everywhere I looked there were obstacles lying in wait. I was deeply excited about my pregnancy and felt the flutter of delight thinking about the tiny life that was growing inside me. And yet this was marred by feelings of anxiety: how would I cope with a baby with, effectively, one functioning arm? Pushchairs are not designed with the disabled body in mind. One has to bring one strap between the legs of (in my case, an incessantly squirming) baby, bring the arm straps over each arm and click one side in place and then work on the other. This sounds relatively simple, but not for a mother with one damaged arm. I trawled through websites and browsed countless shops, but the responses were the same – 'we don't have anything for you I'm afraid'. Even the specialist (few and far between) 'disabled parenting' websites and businesses catered only for wheelchair users – and even then the products were so highly priced they were inaccessible to me. Nappy changing also created a wave of fear; one thing that parents will have to perform relentlessly, and there are no effective solutions on the market to aid someone like me. Bathing my baby on my own would be out of the question, even though there are chairs designed to support them, the constant question in my mind is, 'what if...'? I couldn't be so irresponsible as to even potentially harm my baby. Baby-wearing, which I was keen to do, was only possible with someone else to help me attach her to me. It became conspicuously clear that I would not be able to mother independently and that concerned me greatly. I never felt more disabled than I did during my pregnancy. The baby bump was relatively small, and I didn't have much trouble getting around physically, even in the last month of my prenatal period, but this sense of trepidation and unease perpetually gripped my throat, tight, strangling my joy. I desperately tried to think positive and to hold on to the wisps of happiness and excitement that this new life was bringing, but I also felt it was my responsibility to be realistic and practical. With this in mind, I searched endlessly, and fruitlessly, for gadgets, devices, anything that may make my life as a mother smoother and more manageable. It became clearer and clearer that if you don't fit into the narrow stereotype of a mother-to-be then there is nothing for you.

If I was prevented from preparing for motherhood adequately through the lack of recognition of disabled mothers in the consumer market, then I was adamant that I would place all of my trust in the medical profession. I would not be accused of being a bad mother even before the baby arrived. I duly attended every prenatal appointment; hauled my pregnant body to prenatal yoga; attended every prenatal class; followed all the dietary requirements, cutting out this and that. I was sure that somewhere somehow I would find the calm and glow that is supposed to come with pregnancy. I was desperate to be seen to be avoiding risk, to gulp down and seal off the treacherous reservoir of fear inside me that was threatening to engulf me within its depths.

Nevertheless, the medical appointments were always teamed with pointed looks at my hand, to which I felt – not angry, not a proud disabled woman, but a wave of shame. Every time this happened I could feel my face burning, as if my arm had brought dishonour to my body. This was feeding my anxiety and perception of myself as irresponsible, incapable and inherently ‘not normal’.

The seduction of normalcy rears its furtive head yet again, trying to split parts of me off and force me to disavow them. I know that this is wrong, and I should not be made to feel ashamed of my body, but the social discourses around disability and mothering are immensely powerful. This is echoed in many other stories in the literature. For example, some disabled women in Tarasoff’s 2017 study reported feeling ‘dehumanised’ (Tarasoff, 2017:430) by medical staff during their perinatal period. Similarly, Carol Thomas identified several ‘manifestations of disability’ that the disabled women in her study encountered, which illustrated the ‘problems and issues that the women faced, which were embedded in the social fabric of services and structures, and particularly in the social relationships in which they engaged’ (Thomas, 1997:624). The fact that so little has changed in the twenty years between the two studies shows us how much work there is yet to be done.

This also highlights the assumption of ability in pregnancy. The fact that many hospitals and facilities are not made with the disabled body in mind extenuates the invisibility of disability. As Tarasoff (2017) notes, there is much in the way of ‘informational erasure’ and ‘institutional erasure’ when it is assumed that there will be no need to accommodate non-normative bodies.

This invisibility of disability also manifests itself in the lack of provision for disabled mothers in the consumer market. In Figures 3-9 I have selected a few of the images and advertisements targeted at expectant mothers, highlighting their normative embodiment and reflecting the patronising advice they are bombarded with. Figures 3-5 show examples of women practicing yoga, a healthy exercise deemed to be suitable for the different stages of pregnancy. Women are warned, though, that certain asanas (poses) are not suitable for pregnancy and therefore yoga should be practiced with the aid of a qualified instructor. I readily complied with this endorsement as I had practiced yoga for a number of years, but some of the balance asanas I was unable to do because I couldn't support my body with one hand. In these instances, I felt ashamed of my body and felt incriminating stares coming from the others in the group. I felt like they were saying, ‘If you can’t even do this, how are you going to manage with a *baby*?’ I looked for specialist disabled pregnancy yoga groups but found none. This meant that each class was tainted by my anxiety and feelings of unworthiness. A SiA analysis would reveal the discrimination bound up in the lack of provision for disabled mothers-to-be in the arena of

sporting activities, stemming from the assumption that pregnant women are non-disabled, but knowing this did little to ease my discomfort at the time.



FIGURE 2 (MEDIMETRY.COM, 2015)

Figure 3 shows a pregnant, not obviously disabled body sitting crossed-legged on the grass, with her hands in a heart-shape centred on her bump. The grass and the natural setting, presumably, is meant to configure a more ‘natural’ pregnancy, thus insinuating that women who need help with their pregnancy or delivery are not really performing pregnancy in the way that they should. The fact that the image does not show the head of the woman is significant, reiterating my point about women’s bodies being seen solely as a vessel for the unborn baby.



FIGURE 3 (KUWAITMOMSGUIDE.COM, 2014)

Figure 4 shows three again, not obviously physically disabled pregnant women practicing yoga, performing a difficult asana known as the ‘tree pose’ on a sloping grass verge. I am assuming that the developers wanted to show diversity with the centring of the non-Caucasian woman and the fact that all the women pictured have different hair colours, but they all have a very similar, formerly slender body shape that seems to imply a standardised maternal embodiment. Again, nature - and a natural delivery to be gained through the proper practice of yoga - is implied with the outdoor setting.



FIGURE 4 (TIWARI, 2014)

Figure 5 actually states that, through yoga, an expectant woman can have what is deemed to be a ‘normal’ delivery. Again, this image is of a young, presumably able-bodied white woman, upholding the view that mothering is only an option for a limited number of people. Figures 6 and 7 indicate some of the patronising advice targeted at pregnant women.



FIGURE 5 (DADDYTYPES.COM, N.D.)



FIGURE 6 (HEALTHCENTER.IO, 2014)

Figure 6 features an attractive, not obviously disabled, formally slender pregnant young white woman, holding a glass of beer. The beer, on closer inspection, is non-alcoholic. The advert seems to be saying that pregnant women can still be sexy and participate in their normal activities, although the social forces of bio-power would invite disapproving looks and may force the woman participating in such activities to justify her actions.

Figure 7 pictures the healthy food required for a balanced pregnancy diet. This insinuates that the mother should ignore cravings and aversions and eat ‘responsibly’, assuming that the mother will have access to a wide range of choices and again, ignoring the impact of poverty on the diet. This again demands that a mother put her needs after those of the unborn baby’s,

and ignores any dietary requirements/choices (such as vegetarianism/veganism or allergies) made by the mother. It also implies that any digestive problems in the child is the fault of the mother through exposure or lack of exposure to certain foods in utero. This image supports the concept of the scientisation of pregnancy introduced earlier, with the person offering the advice wearing a white coat. Figures 8 and 9 denote the importance of skin care during and after pregnancy.

**SKIN TO SKIN TOUCH
MAKES A DIFFERENCE**

**THE BENEFITS OF MASSAGE
DURING PREGNANCY:**

Studies show that South Africa has a high percentage of lower birth weight babies. 15-20% compared to 7% in First World nations. Massage during pregnancy has been shown to reduce these numbers. Recent studies conducted by the Touch Research Institute have proven that massage during pregnancy has benefits for both mother and baby:

- decreases obstetric and postnatal complications
- decreases anxiety and stress hormones
- reduces sleep disturbances
- lowers levels of leg and back pain

HEALTHY, BEAUTIFUL SKIN ALWAYS

JOHNSON'S® Pure Tissue Oil is a powerful and effective natural moisturiser. A unique blend of Soybean, Sweet Almond and other natural oils that boost the skin's hydration and encourage overall health, this formula is non-greasy and absorbs quickly.

FOR BEAUTIFUL SKIN AND A
BEAUTIFUL PREGNANCY, START APPLYING
TISSUE OIL AS EARLY AS POSSIBLE
FOR BEST RESULTS!

Johnson's
healthy skin
PURE TISSUE OIL
WITH NATURAL SOYBEAN OIL

- reduces the appearance of existing scars and stretch marks
- prevents new stretch marks from appearing
- rehydrates dry and itchy skin, leaving skin softer and more supple for longer
- reduces the appearance of uneven skin tone that can occur with stretching
- improves firmness and elasticity of the skin

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0860 410032
e-mail: jjs@its.jji.com

RESULTS ARE VISIBLE
IN 6 WEEKS

WHALLEYS 30012

FIGURE 7 (PARENT24.COM, 2008)

Although this advertisement is targeted at a South African population, I believe it still has salience here. The advert uses evidence from 'studies' to compare the birth weight of children born in South Africa to the weight of children born in first-world nations - although it is fair to say that the institute that carried out these studies (The Touch Research Institute) may well

have had a vested interest in reporting that touch during pregnancy decreased the instance of low-birthweight babies. Again, this seems to downplay the effect of poverty and inequality. The advert features a young, not obviously disabled, fair-skinned, pregnant African woman with her partner standing behind her looking lovingly into her eyes. This reinforces the idea that pregnancy and motherhood should only occur in a committed, heterosexual relationship.

MAGAZINE AD DESIGN

Advertised in *Pregnancy and Newborn* & *Fit Pregnancy* magazines

**RECOVERY
CAN BEGIN
BEFORE YOUR
BABY
IS BORN**

Accelerate your recovery, increase stamina and restore your body after your baby is born. Atlas is a 2-IN-1 Transitional band, the pregnancy band that transitions into a postpartum band, back support, plus hip shaper. Atlas 2-IN-1 Transitional band gives you 360 degrees of even support—uplift and enhance-tone.

Got To Have It!

You Only Need One!
Atlas 2-IN-1 Band. Created by The
Trusted Makers of Cinch Tummy Wrap

The Band Specialist

www.myatlasband.com | Sold in U.S. & Canada |

FIGURE 8 (LINTON, 2012)

Figure 9 is an advert featured in many pregnancy magazines for a specialised support band that purports to give both pregnant and postpartum mums the chance to ‘accelerate your recovery, increase stamina and restore your body’ after the baby’s birth. This plays on the idea of a ‘perfected’ body, one not disfigured by scars or unsightly skin, which any mother in her right mind would want to restore once the tedious process of the baby’s birth is dealt with. The advert features a happy, white, not obviously disabled pregnant woman and another happy, white, not obviously disabled woman who, presumably, is meant to have recently given birth. Both these women are young, blond, slim, attractive and, crucially, show no outward display of disability, symbolising again the kinds of woman deemed permissible to mother.

These images and adverts- and the lack of obviously disabled women pictured amongst them - epitomise the representations of pregnancy and early motherhood that disabled women in the western world contend with each day. There are very few ‘expert driven’ books targeted at

disabled mothers, very little advice, and a colossal amount of societal dissuasion, evidenced by the amount of children who are taken into care on the basis of the mothers disability alone. No wonder, then, that many disabled mothers like me wish to morph ableist ideals and blend in to the background as much as possible. In the next section of the chapter, I am going to take the reader through another manifestation of ableism, highlighting again the mistrust of disability when it becomes apparent, manifesting itself as a benign operation with the safety of the child as its primary concern.

8.5 ‘Prevention Science’

In UK family policy and practice, ‘early intervention’ schemes are set to monitor children marked as being ‘at risk’ (White & Watsell, 2015). This has the benign objective as being in the interests of safeguarding the health and development of vulnerable children, but there may be something more at play here, particularly when we take a closer look at the targets of such interventions. Schemes such as the Early Intervention Foundation are enlisted to provide surveillance on groups deemed deviant in society; the socially disadvantaged, women living with mental illness and disabled people in particular. Women who display signs of anxiety in pregnancy are also targeted, with the recrimination that the increase in production of the stress hormone cortisol negatively affects the foetus. In my case, the vast majority of the maternal anxiety I went through was a result of the surveillance I felt I was put under to be the perfect mother *despite* my disability, and a sinking feeling that there was no path for me to follow, no adequate support for someone in my position. This anxiety was not helped by the insinuation that this fear and uncertainty were potentially harming my baby. The biopower around pregnant bodies persists into the early childhood years, and cultural tropes around ‘proper’ attachment are heightened. As Allen (2011:15) chides:

Recent research also shows insecure attachment is linked to a higher risk for a number of health conditions, including strokes, heart attacks... people with secure attachment show more healthy behaviours such as taking exercise, not smoking, not using substances and alcohol, and driving at ordinary speed.

The shaky evidence cited for these claims is brushed over, highlighting the hegemonic clout given to supposedly ‘expert scientific knowledge. An ‘unhealthy’ lifestyle is supposedly the root of all social ills, and therefore citizens, especially women, are highly encouraged to acquire and maintain healthy ‘choices’. By recasting poor nutrition, living in squalid conditions and normative ideals of inactivity as parental ‘choices’, the state is absolving itself of liability in relation to the perpetuation of poverty. No leniency is given in this view to the long hours

worked by many in low-paid jobs, or to the relatively low cost (and poor nutritional value) of most convenience foods. As many disabled people are unemployed or have low-paid jobs, this has particular relevance in assessing their social position. This leads policy and practice away from working to rectify social disadvantage, and back yet again to a focus on changing individual behaviour. This has been furthered by the interest and cultural authority given in popular press to biological sciences. Epigenetics is the theory that supposedly provides an indisputable link between the environment and the DNA blueprint (White & Watsell, 2016:1), relentlessly binding lifestyle with biological composition. This has significant repercussions on reproductive liberty, and paints women who don't conform to the ideal picture as tainted - and thus having the ability to taint her offspring, if she does not change her life in dramatic ways. This view equates the socially disadvantaged as being also '(epi)genetically damaged' (Meloni, 2016:221, cited in White & Watsell, 2016:13). This, in my view, is eugenics by the back door, and it is a terrifying prospect for the future of society. This is where the 'new' science of epigenetics relies on and is informed by disability, with the insinuation being that evidence of disability automatically renders life invalid. It also relies on conventional idealisations of neoliberal motherhood; implying that the responsible mother would choose a partner with no family history of disability or abnormality, in order to give their child the best start in life. In an ableist sense, we as a society have been ideologically informed that this does not include disability. This is incubating the ideal neoliberal citizen from beyond the womb.

8.6 The 'Now or Never' Complex

David Watsell and Sue White (2012) penned an article for the journal *Families, Relationships and Societies* heralding the potentially dangerous consequences of the obsession and cultural authority given to neuroscientific imagery and discourse, warning that this effectively stifles important debate around parental expectations and state obligations. The rationale for this paper is based on the current popularity in policy circles of epigenetics, particularly the commonly accepted (and publicly promoted) theory that the first three years of life are critical in infant brain development. These authors argue to the contrary, that 'plasticity and resilience seem to be the general rule' (Watsell & White, 2012:397). The myth, they say, that the first three years are crucial is a powerful one because it purports to explain away so many social ills, but according to these authors the scientific evidence that these claims are made upon have been oversimplified and misinterpreted. It is not disputing that the early years are a critical time for infant brain development, but what this article *is* disputing is the *irreversibility* of factors affecting the psycho-social development of the infant. The insinuation that the first three years

are critical are based on precarious scientific research, and the policies and practices resulting from this viewpoint ‘may lead in some circumstances to inappropriate labelling or the removal of children from typical experiences, thereby reducing the possibility of self-righting corrections or compensatory growth spurts’ (Shonkoff & Phillips, 2000:364, cited in Watsell & White, 2012:405). So potent are the spells cast by neurological imagery, the inadequacies of the reports carried out by and for governmental organisations are dissipated and the tenuous scientific grounds they rest on are minimised - so long as they include a brain scan as they are ‘a fast-acting solvent of critical faculties’ (Tallis, 2011:280, cited in Watsell & White, 2012:406). Poverty and deprivation are social ills that do not necessarily result in delinquent behaviour. The threats to the brain from perceived extreme deprivation and inadequate nutrition are not a straightforward outcome of negligent or chaotic parenting, but the direct association between the two can lead to the immediate labelling of certain parents instead of offering helpful and sustained assistance. For example, inadequate nutrition may result from poverty, or maybe even lack of knowledge of digestive disorders such as lactose intolerance, but they are blamed on the techniques employed by the parents.

I am forever haunted by the assumption that the first three years are a crucial, and irreversible, period for the development of the child's brain. I know through experience the effects that a dysfunctional brain can have on one's life, and don't want my child to have to go through that. Even though I know in my head that these reports are probably bullshit, and definitely support the mother-blame that is so characteristic of neoliberalism, in my heart I think, 'what if...?' What if these stories are in any way true? What damage could I have already done to my precious child? Moreover, what damage will occur if I have to leave her for three months to be closer to my university, as my contract stipulates? Again, this is where the conflicting ideologies of motherhood and neoliberalism slam against each other, producing conflicting imperatives in which I can only see loss to all involved. From somewhere I feel a need to fulfil my obligations to being a good neoliberal citizen, and that means being selfless in the name of work and productivity. But how can I do that and be a good mother, which requires making my child's needs an absolute priority?

My narrative here reveals the damaging effects that the propensity of mother blame, as a consequence of the illusion of individual ‘choice’, can have on the psycho-emotional self-worth of individual psyches. In sharing this story, I hope to reflect the difficulties of being a parent in neoliberal times, and how easy it is to be spellbound by reports claiming to have scientific validity.

In this chapter we have ruminated on the effects of the increased cultural authority given to processes of medicalisation in pregnancy and childbirth and I have attempted to probe the resulting consequences of this for disabled women. With the success of in vitro screening, the

actual occurrence of congenital disability is in question. It is not the purpose of this thesis to judge anyone relating to the decision to terminate or not, as this is often a very complex, personal decision that may have little to do with disability prejudice, but the point I am making here is that through these advances there is a potential to eradicate congenital disability. I am proof that this eradication does not mean that impairment will not happen later in the life course, but the drives behind the epigenetic movement carry with them a worrying eugenic propensity. The forces of biopower are a restrictive impediment for all women, but I argue that through the study of ableism, we can come to see the particular ramifications of biopower for disabled mothers. There are a plethora of overt and covert ways in which this ableism asserts itself in practice, ranging from the undisguised aversion to disability through practices of prenatal testing and the insinuation that disability should be avoided, and can be through the mother's careful adherence to the strict guidelines set out for her in pregnancy. Not drinking alcohol, for example, can erase the occurrence of Foetal Alcohol syndrome in babies, or taking a daily dose of folic acid to reduce the possibility of neural tube defects. There is a moral and economic link to the aversion of disability, tied to misleading and one-sided depictions of life with a disability: (*'How can a parent wish a life of misery and pain onto their offspring?'*); (*'how can a parent justify the added cost to the taxpayer of the medical and social care that disability inevitably brings?'*). Ableism also manifests itself in more latent ways, for example in the depictions of overwhelmingly non-disabled mothers-to-be in images and adverts, subliminally prioritizing able-bodied life. This continues through the lack of provision for mothers with differential embodiment or alternative needs in hospital settings and recreational facilities. This clearly demonstrates at best a hostile attitude to disability in the arena of pregnancy and motherhood. I hope that through the engagement with the critical study of ableism, I have begun to weave a nuanced critique of ableism's performance that can be used for the wider expulsion of ableism in society.

CHAPTER NINE: CHILD-DEVELOPMENT THEORIES AND THEIR IMPLICATIONS FOR MOTHERING

9.1 Overview

In this chapter, we will see the extent to which the normative conjectures of psychoanalysts writing almost 100 years ago have influenced the childcare practices of today's (Western) society. Woven into this analysis will be excerpts from my diary, providing contextual evidence of ableism in practice and relating my experiences to the broader cultural phenomena of neoliberalism and clandestine government control. This chapter will also seek to illuminate the instances where the claims of the psychoanalysts that I will outline here coalesce and merge with ableist suppositions and so serve to constrain the proportion of women deemed permissible to mother. It will introduce and analyse some of the psychoanalytic concepts that are beneficial to the analysis of ableism, as well as the ones that can be implicated in its production. This chapter will take the reader through some of the tensions I experienced in the early months of my child's life with societal directives, driven by normative developmentalism, to assess both my skills as a mother and my baby in relation to established norms. My narrative of breastfeeding will be extrapolated and interrogated as this reflects a need in me to conform to standard ways of mothering, exacerbated by the beliefs and practices of the community of mothers that I have grown to draw support from. Finally, this chapter will introduce what, exactly, are the values associated with being a 'good' mother and in what ways these deny disabled motherhood. This will explain terms such as 'intensive motherhood' and 'attachment parenting' which are in danger of becoming so absorbed into the collective cultural genealogy, so taken-for-granted, that we struggle to distinguish them as ideologies and therefore devise ways to resist them.

As I suggested in Chapter Seven, many of the ideas, myths and mandates for 'mothering well' can be shown to derive from the theories of psychoanalysts and, later, developmental psychologists. These 'experts' in child development lay out tacit rules of interaction with a nauseating undercurrent of ableism and an overwhelming proclivity to emulate the norm. What we shall see next is a brief outline of the theories developed by Freud, Klein, Bowlby and Winnicott and the consequences for all individuals who mother.

9.2 Freud

Sigmund Freud believed that the way in which parents, especially mothers, negotiate their child's apparent sexual and aggressive desires had a great bearing on their future development

as adults. He proposed five major 'stages' in a child's psychosocial development: oral, anal, phallic, latency and genital. Freud postulated that failure to gratify the infant's needs at any of these stages would lead to fixations, and further mental 'distress' in the child's adult life (Freud, 2009). For example, problems encountered in the 'oral stage' may lead to excessive behaviour (eating, drinking, smoking and so on) and other issues of dependency throughout the adult's lifespan. One of Freud's lasting theories was of the development of the personality, starting with the unconscious impulses which he called the *id*, which is the libido or essential force governing innate desires, wants and needs. This theory has, by and large, been accepted by the general public as a sound fact, in spite of all of the later critique of Freud's theories (Dvorsky, 2013). It is now common parlance to believe that a baby is reacting to his or her libidinous desires, and that they have not yet, and cannot be expected to, develop the sensibilities to adapt to the bodies and capabilities of individual parents. This is one manor in which the uncritical acceptance of psychologist's theories can be damaging to disabled parents. This is evidenced in my narrative;

8/09/17

This was my last Friday with Jasmine on my own, and it was a disaster. I was really looking forward to spending the day with her without any time restrictions or appointments we had to keep to, but today she refused to let me put a clean nappy on her twice – I had to get help from one of the neighbours which was embarrassing. Of course, when he was there she was sweetness and light, and let me put a fresh nappy on with no problems at all. Then she wouldn't go down for her morning nap. I was extremely tired as she hasn't been sleeping well, and she was breastfeeding from 5.30 in the morning, so I was going to nap with her whilst feeding her. We finally got a little sleep but then as I was about to try to take her out for a walk and to get some much needed groceries, she did another poo so the battle was on again.

*I don't dare even attempt to put her in the new buggy when she's being like this, thrashing around and screaming - evidence, Freud would say, of the *id* impulse of aggression -, although some fresh air and a change of scenery would have probably done her the world of good.*

I just feel totally alone, isolated and it feels like I can't talk to anyone. It's very difficult to think that it's not just me being the shittiest mum ever, because whenever anyone else is around she's fine. I just don't know what to do. I don't feel like I can talk to the other mums in the group we have – they are all so accomplished and competent, and I can't even put a nappy on my daughter after over a year of practice. I feel like I'm back at square one.

*I don't know what to do. I just want her to be happy and safe. I don't want to admit it but I feel like I can't cope. Perhaps this is a real demonstration of her '*id*' - this battle that seems to occur between her and I may be just her way of demonstrating what she*

wants? Or maybe she doesn't know what she wants, she just knows she isn't comfortable for some reason? But why is it always against me?

17/09/17

Jasmine is still not sleeping. Well, she goes to sleep with no problems but can't or won't sleep for more than four hours in a row, five if we're lucky. I've read all about sleep cycles and know that the first cycle is the longest and deepest, but we have to have a life too so I'm not going to bed at 7.30 every night! When she can't get back to sleep on her own, she screams in her cot until either of us picks her up, then she goes back down for an hour or so, and then repeat ad infinitum. I guess this is meant to be 'normal'? Well not according to our paediatrician - she said, 'Well, she's one now and normal weight, so she can sleep through the night!' (Does someone want to tell her that then?) I struggle to think clearly and don't know what to do. I don't want her to have a 'fixation' with the oral stage (through breastfeeding) because of me, but I don't know what to do!

A preliminary social psychoanalysis of my narrative reflects a deep need in me to emulate the norm, to conform to exacting standards. This was partly driven from my fear and lack of knowledge as a first-time mother, and partly because there are no disabled mothers in my social network or in the media that I could take recommendations and encouragement from. I felt lost and alone, and did not know where to turn for guidance. A normative psychoanalytical reading of my stories here is deeply individualising, and succeeds in creating profound shame around my interactions with my baby. The assumption, taken from a thin understanding of developmentalism that a 'normal' baby will progress smoothly through the supposed stages of development can be erroneous, further enforcing mother-blame and de-politicising the ideology of motherhood. The focus on the mother-child dyad individualises any problems that may arise, ignoring the implications of internalised disablism onto a disabled mother's self-concept and side-lining the problems encountered operating as a disabled mother in a disablist world (Malacrida, 2009). In my mind at the time, these problems were further evidence of failure – failings that happened solely because of my disabilities. In actual fact, though, they could be attributed to the complex interplay of social anxieties and perceived pressures of motherhood that I had readily absorbed, propelled by the incessant focus on able-bodied mothers to the exclusion of disabled ones. The impact of child-development theories, and the cultural obligation to act in accordance with them, has certainly been shown in my parenting style – or, at least, the style that I felt I needed to adopt in order to be recognised as performing to the standards of ideal motherhood. This stretched my limits and left me exhausted, but the cultural imperative is not to count the feelings and needs of the mother, so this sentiment had

nowhere to go other than be swallowed down inside myself, perpetuating the cycle of internalised disablism. Psycho-emotional disablism (Reeve, 2014:93) ‘arises from the relationships a disabled person has with themselves or other people ... acts of invalidation’ that occur through the hostile stares or critical beliefs of a disabled person’s abilities. The negative beliefs a disabled person holds about themselves has been referred to by Reeve (2014) as ‘internalised oppression’, and can be incredibly damaging, as my narrative shows. The emotional energy of trying to emulate the ableist norm ‘is forever at risk of fracture and exposure, denies access to alternate ways of being in which disability is associated with diversity, as a site of potential resistance and possibility’ (Reeve, 2014:95). This is where, Reeve (2002) notes, forms of psychoanalysis can be used to shed light on the formulation of identity constructions. Internalised oppression can be described in terms of object relations theory, wherein the disavowed parts of non-disabled people are projected onto disabled people, who are configured as eternally Other (Reeve, 2002:495). This is where social psychoanalytical theories can be useful to the study of ableism in motherhood.

The broader neoliberal project of ‘intensive parenting’ (which will be a focus of this chapter) is evidenced by the incessant focus on parents making choices which are deemed to be good or bad, irrelevant of the social conditions that enforced them. The influence of wider systems upon families is ignored, further pathologising mothers. This, Lucas (2011) argues, is because ‘the focus on parental behaviour is ‘the hegemony of current policy discourse’ (Lucas, 2011:189, cited in Jarvis & Georgeson, 2017:33). By making the notion of ‘choices’ benign, neutral, and open to everyone, regardless of the social position of the family, the government succeeds in the perpetuation of the supremacy of the market economy in which sole parents are blamed for their success or failure in producing the idealised citizen of the future. Jarvis & Georgeson (2017:31) argue that parenting ‘has been transformed into a set of skills that the discerning parent must acquire in order to be considered as a ‘good’ parent’. In this way, the production of the idealised citizen is tied to market forces and the consumption of advice targeted at this population.

The issue of sleep is also suffused with contemporary notions of what it means to be a responsible, conscientious, consuming parent in western society, with a plethora of books written on the subject. The forces of biopolitics (which we shall cover in more depth later), in conjunction with a non-critical understanding of developmentalism, encourage us to seek help from medical or child ‘experts’ in order to guarantee a productive night’s sleep for the baby, as, don’t you know, sleep is when the baby develops. This also sheds light on how influential

theories of parenting that dominate popular culture can be on one's own parenting styles, be they consciously adhered to or operating as dysconscious reasoning for one's actions. The way in which the postulations of psychologists, operating from a strict neurotypical angle, can negatively affect the self-belief and self-worth of disabled mothers shows how ableism infiltrates these theories, and negatively affects the place of disabled people in society.

Freud advanced (Parsons, 1958) that as the *id* develops in humans before other components of the personality, the 'natural' desires or needs of the infant will be expressed as primal desires, untempered by the needs and desires of others in their environment. This certainly seems to be the case, as my narrative shows. This seems to reiterate role of the parent as an endlessly patient, understanding, selfless nurturer who must never put their needs even close to first. However, the common perception of the *id* as 'irrational' is perhaps ambiguous - it is probably a perfectly reasonable response to having to stay still (to put a nappy on for instance) when you want to move around; or a response to having filled said nappy; or a response to waking up in the night when you are still tired.

Freud postulated that, after the *id* we develop the *ego*, which serves to regulate the *id* and is a referee, so to speak, between the irrational *id* and the *superego* and develops in response to living in the world – the 'reality principle'. Finally, the *superego*, or the 'parental voice' which represents the social rules of the society in which we live. This suggests that the role of the parent is to enculturate the child into society's strict implicit and explicit moral codes, which has the potential of transferring any benign or damaging beliefs through to the child, continuing the socialisation process. Freud's theories sparked a wave of speculation around the developing life of the child (Parker, 1997). It was later suggested that many of his theories were largely unsubstantiated but his views were widely popular especially amongst parents who sought to understand how to rear their children (Freud, 1980). This spawned a desire amongst psychoanalysts to procure a 'psychoanalytic education' (Freud, 1980:4) in parents with the aim of preventing future neuroses in children. Although Freud himself admits to the sometimes confusing and contradictory advice given to parents over the years due to new research and 'discoveries', the recommendations and guidance were often taken by popular culture to be gospel. Many of his theories have since been under vigorous attack from researchers and psychoanalysts and have been proven to have no scientific basis, yet still they retain a legacy of acclaim and authorisation. Why? According to Goldhill (2015), America and Europe were going through a period of particular self-obsession during the time when many of Freud's thoughts were widely disseminated in the Psychoanalytical Press, the publishing arm of the

International Psychoanalytic Association, not only to research journals but to newspapers and magazines throughout the world as well. It is perhaps because many of his theories were considered radical that they stood the test of time. Theories such as the Oedipus complex (wherein boys are seen to have a jealous, sexual obsession with their mother) or ‘penis envy’ (wherein girls apparently experience anxiety because of the lack of a penis) are among the more far-fetched of Freud’s theories but are still widely known and preserve some credence amongst the wider public. Psychoanalytic concepts have been popularised in numerous television dramas, literature and other media perhaps *because* of their outlandish nature. Freud drew from mythology to give his conjectures added depth and plausibility, and the added dramatic flourish is compelling. This gives some explanation as to the durability of his claims, however lacking in investigative robustness. Ian Parker, in his 1997 book *Psychoanalytic Culture: Psychoanalytic Discourse in Western Society* points out that possible errors were made in the translation of German into English, and far more precise estimations of age and durability of, for example, Freud’s theory of personality, than he may have intended (Parker, 1997:28). This, he stated, may have been beneficial for the psychologists in Britain and America as it gave support to the insinuation that they, by acting on and developing Freud’s theories, were engaging in ‘proper’ scientific study of the mind (Parker, 1997). Freud’s theories, or more specifically, the culturally understood interpretations of his theories, helped to secure the importance of the nuclear family, with each person fulfilling their (narrow and limited) role as the only safe way to raise a child. Pfister and Schnog (1997) articulate the effect that psychoanalytic theories has had on American culture succinctly;

Although multifaceted and perennially rescripted, the mid-to-late 20th century common language of selfhood can be said to rest on a foundation of accepted ‘truths’ and practices that include the following: an arsenal of basic terms for the inner self and its dysfunctions (ego, unconsciousness, repression, Oedipus complex, neurosis); a structure of the mind imagined in terms of ‘rational’ conscious processes and ‘irrational’ unconscious desires; a developmental model of the self which posits the self’s growth through psychosocial stages; and a method of cure which depends on a patient’s talks with a trained analyst, assumes the primary importance of a patient’s family in the etymology of his or her symptoms, and presumes the possibility of a patient’s self-improvement.

(Pfister& Schnog, 1997:4)

This has no mention of the economic circumstances of the ‘patient’, or indeed the state’s responsibility for ensuring the welfare of its citizen. The authors argue that through popular media such as literature and films, the thoughts of psychoanalysts such as Freud and Bowlby

filtered down to become common knowledge among the bourgeoisie. The idea that there existed inside all of us a ‘self’ that could be improved upon with adequate care and attention (which in itself assumes a certain amount of free time and energy) is at the heart of humanist thought - and this fits snugly into neoliberal concepts of self-regulation and the prizing of self-sufficiency. No wonder, then, that the state was eager to circulate these (narrow and normative) ideas. The continued proliferation of these ideas, and the cultural authority given to them, individualises and separates mothers from each other, isolating them and effectively proportioning blame onto the particular family circumstances, which is evidenced in my earlier story of self-blame and isolation.

9.3 Klein

Melanie Klein (1959), another well-respected psychotherapist, conducted play-work with children which yielded many new insights. She followed in Freud’s basic personality structure, however she proposed that the ego exists from birth and serves to defend the infant from anxiety caused by what the infant perceives as aggressive influences both from within and from the external world (Klein, 1959). A brief discussion of Klein here is useful because her work contributes to the wider social psychoanalytical cultural imaginary that permeates the western world. This can be gleaned from a cultural reading of the influence of psychoanalysis, and the profound effect on mothering ideology. What are useful about Klein’s theories are the ways in which she discusses the splitting off of parts of ourselves through a need to disassociate the aspects that are in some way distasteful. She also theorised about the ways in which we internalise repressive norms and about the ways in which we resist them (Layton, 2007) both of which have relevance to this chapter.

Klein’s most important theory in respect to this project is the theory of object relations – specifically the mother’s breast as representing all gratification and frustration: ‘The mother in her good aspects – loving, helping, feeding the child –is the first good object the infant makes part of his inner world’ (Klein, 1959:294). However, the breast or bottle also represents a source of frustration and consequent aggression for the infant when the mother removes it from the infant’s grasp. This, Klein surmises, leads to ‘splitting’ of the object. This theory served to bind the mother-infant relationship more tightly and thus, like Freud, correlated the success or failure of this attachment with future neuroses and mental ‘imbalance’ in later life.

Breastfeeding was something that I thought I would try and do for the first six months at least. When I first started though, it was incredibly painful and I began to dread the moment when she would need feeding again which - as many mothers will contest to -

was seemingly whenever she was awake. I was determined to persevere though, perhaps because I had absorbed the essentialist and deeply normative trope around what it means to be a good nurturer - and that meant breastfeeding. I felt I needed to continue to ignore my pain because I had read all about the essential nutrients and antibodies that would be passed down to her in my milk that could not be concocted from formula. After around six weeks the pain started to recede, and I began to enjoy it. It became 'our thing' - something that no-one but me could do, and it was special. That kind of made up for all the 'normal' things that I couldn't do. Now, I sometimes feel like I'm scared to lose that connection. Sometimes I think she only likes me because of that. And sometimes I think that thought is ridiculous.

Again, this story re-emphasises how the uncritical acceptance of psychologists' theories permeates self-perceptions, and have the potential to be deeply damaging. Breastfeeding also assumes a normatively working female body. This highlights the depths of ableism, and shows how these thoughts can become naturalised and neutralised, and utilised by the public without realising their ableist undertones.

9.4 Breast is best? Cultural tropes around infant feeding

Even now when I see a new-born baby with its mother and s/he is being bottle fed, I find myself feeling superior - even though I have no idea whether the milk in that bottle is expressed milk, or whether that particular mother has had a problem breastfeeding, or any personal history of the duo. What strikes me is the normative way in which I have accepted breastfeeding as the 'right' thing to do. This has the power to make mothers who, for whatever reason cannot fulfil this social obligation, feel immense guilt. The dominant invocation that 'breast is best' is bewitching - seductive in its magnetism. Indeed, Li et al. (2007:122) have stated that there is a need to educate the wider public that 'breastfeeding is the best method of feeding and nurturing infants. Paediatricians and other health professionals should recommend human milk for all infants for whom breastfeeding is not specifically contraindicated'. Breastfeeding is also widely considered by a vast proportion of health professionals to be the best way of securing an emotional bond between mother and child. Moreover, the failure of 'bonding', wherein it is reputed to be essential that the infant and mother form and maintain an intimate alliance from birth onwards, is according to Lee (2008:470) deemed to be responsible for a host of social ills;

Problems in the early mother-child relationship are considered from this perspective not only damaging for individuals, but causal in the origin of social problems such as criminality and violence since criminal and violent people are deemed to have suffered impaired emotional development in the early years of life.

This statement makes me feel incredibly guilty, particularly with reference to my narrative in Chapter 7, and yet I am well aware of the political and economic motives behind this drive.

Part of my brain still retains a critical view around this notion and the way in which it pathologises mothers, but the lure to believe this nonsense is scarily compelling.

However, a report by Boyer (2012:552) indicates that, although nursing is widely accepted and promoted in the UK, breastfeeding mothers are routinely ostracised and made to feel unwelcome in *public* places. Boyer argues that,

...despite being promoted by policy, breastfeeding women are marked and marginalised in the public sphere in the UK through a process of intersubjective affective practice...I propose that breastfeeding women are expected to act so as to maintain public comfort (i.e., the comfort of others) or risk censure; and that this schema is further sustained in the way that breastfeeding is 'provisioned for' in the built environment in the form of lactation rooms. I suggest that these spaces, practices, and affects can serve to constrain women in the UK from breastfeeding in public.

Moreover, a damning report in the 2016 edition of *Journal of Lactation* entitled 'UK views towards breastfeeding in public: an analysis of the public's response to the Claridge's incident' (Morris et al., 2016) describes, in my view, bigoted and parochial attitudes towards breastfeeding mothers. The report describes an incident in 2014 where a mother was trying to breastfeed her infant in the coffee shop of the prestigious hotel, and she was asked by a member of staff to cover herself with a napkin. The article recounts some of the petty justifications for overtly rejecting women's right to breastfeed in public stated on various websites in response to reports of the incident: '...breastfeeding is natural...going to the toilet is natural, do you just pee into a bucket next to you or do you get up and go to the bloody toilet?...', and 'Why do women feel it [is] their right to get their breasts out in public to feed babies?' (Morris et al., 2016:12). This ignores the conflicting 'right' of men to display pictures of breasts flaunted seductively on the walls of workplaces and such.

However, according to The National Academy of Sciences, Engineering and Medicine (1991), there have been very few conclusive studies carried out as to the possible negative maternal effects of breastfeeding, particularly extended breastfeeding (beyond the first year of the infant's life). The potential reasons for this omission may be that the current cultural imperative is to promote breastfeeding practices, but the very real possible consequences - such as the increased risk of osteoporosis - are worthy of investigation. I will argue throughout this project that we are in an era of 'intensive motherhood' (Hays, 1996) and the cultural tropes around feeding and nurturing babies does not escape this bioethical minefield. Indeed, as Lee

(2008:468) states: ‘How mothers feed their babies is experienced as a ‘measure of motherhood’ (Kukla 2005)’. I recently saw a report (delivered on my Facebook feed) by BBC Mundo (October 2017) about the microbes and the sugars contained in breast milk that babies cannot digest. This study suggests that the sugars are not designed to feed the *baby*, but to provide nutrition for the essential bacteria that help to prevent certain infections that are common in newborns, especially preterm babies. This report uses a number of scientific terms, perhaps to overwhelm the general public into believing what the ‘experts’ say. This, and many other such reports, serves to exert increasing pressure on mothers to breastfeed, painting those who choose not to as selfish, contemptible, and causing unnecessary risk to their babies.

However, many mothers cannot or *will not* breastfeed - perhaps because of the discriminatory attitudes towards them as we have seen. Paradoxically, the public hostility targeted towards those who, for whatever reason, will not breastfeed is palpable (see especially Lee, 2008), yet it seems to be in direct opposition to the hostility directed by some members of the public towards breastfeeding mothers. It seems that mother’s cannot win, however they chose to feed their babies. They are made to feel guilty whichever choice they make.

Ok, I relent. We’re going to try formula, just at night. I really don’t want to do it, but it’s taking over an hour to breastfeed her at night, and I’m so tired! We’ve been giving her what we call ‘emergency’ bottles; a little pre-made thing if we were out. I didn’t want to even give her those – I wanted to exclusively breastfeed until 6 months, but social pressures kind of necessitated it, as people around me perceived I was having ‘trouble’ with breastfeeding particularly when my arms began to get tired and she still wasn’t satisfied. I feel like I’m not listened to, not respected. But then I also feel guilty at not being able to move fast enough for my daughter. I think that Jasmine and I need to develop our own rhythm, me going slightly faster than I’m comfortable with, and her recognising and allowing for my slower pace. We need to move in our own Crip time. Instead, I feel like I am constantly rushed and made to feel not enough. We need to develop a connection in our own time. Everything would have gotten quicker with practice anyway, but it feels like I’ve been made to feel like that’s not enough.

I ask the reader to allow me to break from the flow of the text in order to insert a note on the notion of, yet again, ‘Crip’ time. This pausing is significant, and I shouldn’t have to feel I need to apologise for it... and yet I do. I feel like I need to apologise for taking up more of the reader’s valuable time, for needing to extend and prolong their attention. This need to apologise is bound up in the capitalist-inspired notions of ‘time=money’. But for me, time moves slower and more intricately. I take more time than (I’m guessing) the average person to do simple everyday tasks like getting dressed or making dinner... and that is ok with me. I have amalgamated this aspect into my life as a person. Feeling rushed makes me anxious, and when

I get anxious my hands get jittery and I make more mistakes – a self-perpetuating phenomenon. When I can take my own Crip time, I feel more at ease. Yet the taking of time is considered to be selfish in the dominant narrative of motherhood, as it denotes that the mother is putting her needs before those of her child which – according to the script of motherhood – is unforgivable. Campion (1995:140-141) cites the example of the disabled mother Tiffany Callo being legally challenged on her competency as a mother due to her slowness with changing her baby's nappy. This is used by the legal team as evidence of her incompetence as a mother, and could result in the baby being taken into care. The normative valuing of time is associated with industrialisation and capitalism, where time is money, but seemingly it has no place in the world of motherhood, where the cultural imperative is that motherhood *should* absorb all of the mother's time and energy. An ableist reading here points to the mismatch in cultural expectations.

My narrative shows that I have taken on and absorbed strong cultural associations connected with breastfeeding and the idea of being seen as a 'good' mother. I consciously want seek to repair any 'damage' done to the supposed symbiotic connection that was, in my mind, somewhat fractured at birth, as my opening narrative reveals. It seems like I, as with many other mothers, have taken on breastfeeding with 'almost a religious fervour' (Lee, 2008:12). I feel confident in displaying this act as a symbol of my competence and validity as a mother, and I feel that it somehow makes up for my other incompetencies like struggling to dress her. This very act shows us the complexity of disability's relationship with the normal, *and the seduction and invisibility disabled mothers get from emulating the norm – despite the damaging effects on self-concept*. I readily admit that I perform this act as a symbol of defiance, my way of saying that even though I am unable to do some things that most people would consider normal for mothers to be able to do, I can still do this. I have the battle scars to prove it. I feel that it is of greater importance now to convey this message (although to whom I'm not sure) to balance the decision to give her formula at night. The imperative to exclusive breastfeeding for at least six months has been communicated widely to women via a plethora of messages, and the guilt associated with alternative ways of feeding is profound. 'Bottle feeding', Lee (2008:470) states, 'has come to be represented as not only without benefits, but as a feeding method that incurs a wide range of risks'. This has intricate links to a wider public discourse of child-centred mothering ideology (Lee, 2008) and can be ascribed to the postulation of psychologists (and the hegemonic cultural approval given to their claims). Arguably the most compelling decree to breastfeed is delivered through the insinuation that this method is the only

one that will facilitate adequate bonding for the mother-child dyad. We shall now explore the possible origins and the cultural significance of this ‘bonding’ symbolism.

9.5 Bowlby and Winnicott: The birth of Intensive Mothering?

During the 1950’s and 1960’s, John Bowlby and Donald Winnicott worked individually but concurrently to provide differing theories of child development. Tenets from both theorist’s ideas were later popularised as ‘attachment parenting’, which is strongly related to the ideology of intensive mothering (Hays, 1996) which we shall be exploring later in this piece. Bowlby furthered Freud’s and Klein’s impetus on the uniqueness of the mother-child relationship, surmising that it was the strength of this bond that determined later outcomes in life. He differed from Klein in that he did not attribute neuroses to internal conflict between aggressive and libidinous drives; rather, Bowlby deduced that emotional disturbances in the child were the result of early family experiences, specifically maternal deprivation. Thus he postulated that the cries and signals of the infant were not produced to elicit food but were instead driven by the infant’s need for care and responsiveness. He called this ‘attachment theory’. (For more on attachment theory, see Ainsworth and Bowlby, 1991). It was widely taken from Bowlby’s theory that as the first two years of life were deemed to be crucial for the development of a secure relational bond, mothers should devote the vast majority of their time to establishing and maintaining this safety net – thus having a direct implication for the morality of ‘working mothers’. The historical specificity of these claims is of crucial importance here – these claims occurred after the Second World War when men were returning from war, and women were working in factories in jobs needed by those men. This is where economic imperatives, government forces and popular culture compound to produce limiting directives for women.

Winnicott, as a follower of Klein, concurred with many of her hypotheses, imbuing the salience of the mother-child bond with even more significance. As Chodorow (1978:22) recognises; ‘Winnicott suggests that holding the infant physically in her uterus leads to a mother’s identification with the infant after it is born and therefore to ‘a very powerful sense of what the baby needs.’ Winnicott’s biological determinism is a very powerful tool in keeping the status quo, as we shall explore briefly later. Winnicott suggested that the mother’s inability to predict and thus cater for the infant’s more complex demands as they become older actually facilitates their growing capacity towards independence. Winnicott surmised that the infant learns a greater level of tolerance and develops an understanding between their instinctual ego drives and getting these met. He derived the concept of the ‘good enough’ mother:

A mother is neither good nor bad nor the product of illusion, but is a separate and independent entity: The good-enough mother ... starts off with an almost complete adaptation to her infant's needs, and as time proceeds she adapts less and less completely, gradually, according to the infant's growing ability to deal with her failure. Her failure to adapt to every need of the child helps them adapt to external realities.

(Winnicott, 1953:94)

This concept is a very normative role associated with high expectations, and can be increasingly difficult for the (generally exhausted) mother to manage. It denotes that a significant degree of skill and fastidious attention is needed to balance the desires and the needs of the child. Winnicott proposed that the best method of ensuring the infant's care was to provide a facilitating environment (Winnicott 1960) that involved protecting and developing the nurturing bond between mother and infant. This 'facilitating environment', managed by the mother, would be attentive to the needs of the infant as s/he matures, and would eventually recede in importance. This involves the mother paying fastidious attention to every requirement of the baby, and responding in a way that is deemed morally, culturally and historically appropriate - a mammoth task. The mother must be 'just enough' -not too supportive or else the infant wouldn't develop the 'proper' level of independence, but also never, god forbid, inattentive or lax in the support and guidance she offers. This is the 'goldilocks syndrome' (Connors, 2013) manifesting itself as 'common sense'. The infant and maternal care thus become inseparable. This concept relies on the idea of the mother as an unchanging, static object that is not swayed in any way by the strains of caring with all of her being for another person. This is profoundly unattainable and ableist and yet (as we will see) has come to be expected as the baseline for mothering. This nuanced take on attachment theory that I have tentatively introduced here may be an interesting avenue for disability studies theorists to explore in more depth.

Winnicott reified the idea that the mother-infant bond is sacrosanct. Moreover, he went further than this to hypothesise a symbiotic, unified existence of mother-and-baby as one: '...It seems to be usual that mothers who are not distorted by ill-health or by present-day environmental stress do tend on the whole to know what their infants need accurately enough, and further, they like to provide what is needed. This is the essence of maternal care' (Winnicott, 1960:593). Let's pause awhile to unpack this statement. Firstly, this places great responsibility onto the mother's shoulders, and identifies any mother who is not able to divine *at all times and without fail* what it is that the baby wants, as deviant. The expression Winnicott has chosen here is

significant; *distorted* – meaning tainted, inadequate, and not ‘normal’. Sometimes, however much I would like to ‘provide what is needed’, it is just not physically possible.

During the months following the birth of my baby, I enlisted the help of a ‘doula’. I thought this would be very beneficial, as I (mistakenly) thought she may be able to help me devise ways to manage Jasmine, with dressing and carrying for example. She was a really lovely person, but I expected her to be able to provide more than emotional support. I needed practical help, and fast! Other people in my support network just got frustrated that I couldn’t do it in the way that they could, or that I sometimes forgot what they showed me and needed more demonstrations. This wasn’t helping my (very low) self-esteem and confidence as a mother, and I needed someone outside of the family to offer constructive guidance. She thought that that wasn’t her role at all, and she was just there to offer support on breastfeeding and to talk through my emotions with me. Ok, so we got our wires crossed with our expectations, fine. I thought I could still use someone to talk to though. She was a very strong advocator of breastfeeding (she was still breastfeeding her boy at age two) and what I would later come to know as ‘attachment parenting’. She gave me a book to read called ‘The Continuum Concept’ by Jean Liedloff. The book is about the author’s experiences living in South America with a group of people called the Yequana and the lessons she learned from them. Throughout this book the author delivers a strong message: that we in the West have lost a certain happiness that can only be found through intensive mothering practices. I didn’t get through the entire book, but I absorbed enough to ‘know’ that bed sharing, breastfeeding and babywearing were essential if the baby wasn’t to grow up constantly unhappy.

I severed the relationship with my doula - and stopped reading the book - when she said to me, (in the midst of one of Jasmine’s crying fits) ‘Babies only cry for a reason. You should know by now (5 weeks old) what that reason is and be able to stop it. It’s your job’. I felt like she had taken all the fears that I had previously disclosed to her and rammed them down my throat.

There is nothing I would have liked more than to have been able to pick my newborn baby up unaided and shower her with cuddles and kisses whenever I felt like either of us needed it, but I couldn’t. I desperately wanted to, but as I felt it would be safer for her if I didn’t attempt it. I felt like I would be putting her life in unnecessary danger if I did so as I didn’t know how to support her head and neck adequately. How much of our relationship have I ruined by not being able to do this essential thing? Have I put my child at risk? How can I make it up to her? Will it be possible, or is it too late to do anything about it? I just want to hold my beautiful baby like I see so many other mothers do, but I’m scared I will inadvertently hurt her...

An uncritical psychoanalytic reading of this story would confirm my sinking feeling that I am not a good mother. My disability and my anxiety around handing my baby was evidently blocking the crucial bond with her, evidenced by the way that I was not able to consistently deduce her needs. This is how I felt, encouraged by the non-disabled person I had intended to be a form of support. Both an ableist and a critical social psychoanalytical reading of this narrative, however, would look more closely at my internalisation of disability as incapable

and untrustworthy, and point to how this depiction of myself was affecting my self-esteem and confidence in my new role. It would also interrogate a plethora of factors in my environment, such as the lack of disabled mothers as role models; the experiences during pregnancy; and the lack of physical support I received. It may also implicate my desire to be a 'normative' mother: instead of trying to come up with ways of doing mothering differently, my overwhelming desire was to mimic what I had taken on board as the actions of a 'normal' mother - which, when I was unable to perform these actions in the way that they did them, confirmed my perception of myself as 'lacking', perpetuating the cycle.

Arguably, the ideas put forward by these psychologists specifically have furthered the pathologisation of women and 'mother-blame'. It has caused me in particular to scrutinise every single action and reaction since Jasmine's birth, and, for the most part, to judge myself a failure. Is that solely because of my disability? I suspect not; the idealisation of the 'perfect' mother has to be unattainable, or at the very least *unsustainable* for long periods of time. Sadly theories such as these have become widely absorbed by popular culture and woven into the social fabric as the 'right' way to parent. The mother takes individual responsibility for any offspring she (alone, presumably?) procures, absolving the state from having any duty towards ensuring the welfare of its citizens. Both Winnicott's and Bowlby's ideas, despite being later profoundly contested, have arguably had a great influence on the parenting imperatives today. The historical, cultural and economic effects on the data that many psychologists work with is rarely taken into account, rather their ideas are held up and idealised as the pinnacle of 'good' mothering. As Phoenix and Woollett (1991:21) identify:

By confining many studies of mothers and infants to mother-infant pairs where mothers are married and are observed when they spend their days alone at home with their children... psychologists reify popularly accepted notions of the circumstances in which motherhood should occur.

Psychological studies of motherhood are based on a limited (neoliberal, white, capitalist, patriarchal) strata of mothers and acknowledge a narrow range of maternal behaviours, and the 'specific ideological underpinnings' (Phoenix & Woollett, 1991:21) to many developmental psychological studies is rarely recognised and explicit, rather it is cloaked under the veil of 'normalcy' and other maternal behaviours are labelled deviant. For example, engaging in acts of shared parenting (wherein a child is looked after and cared for by others in the family or the mother's social network) would be considered by many psychoanalysts to be significantly inferior to having the child solely under the mother's care. We shall explore the possible

motives behind this narrow, constricted approach to parenting that serves to reify neoliberal forms of social structure later in this chapter, but let it be stated for now that these psychologists helped to create an ethos in which the idea of raising a child outside the typical ‘nuclear’ family was, and conceivably still is, a ‘risky’ act. Psychology mirrors the demands of the society and economy in which it is produced, and therefore reflects a decidedly ableist, restrictive differentiation of mothers termed ‘good’ and mothers labelled as ‘bad’. Many psychologists argue that the mother’s attitude and mothering style has the greatest bearing on the child’s subsequent development. For example, the mother must never be angry or impatient with their little ones, must always be attentive to their every need. This idealisation perhaps subliminally restricts the amount of children it is commonly regarded as moral to have. This tends to overlook the complexity of mothering in a range of different circumstances and social positions, but instead construes a narrow definition of ‘good’ parenting.

The next section of this chapter will begin to explore the values embedded in notions of ‘good mothering’. Following Dan Goodley (2014) and Fiona Kumari-Campbell, my aim here is to use the assumption of able-bodied and able-minded motherhood to shed light on the beliefs, principles and standards underpinning the infeasible, austere articulation of the ‘ideal mother’. My intention is that by naming and explicating the commonly held figure of the ideal mother, we can come to expose the ableism lurking within it. Although I am drawing on the concepts derived by other theorists, I feel that the analysis that comes through my work is unique to me, and is therefore a novel contribution of my thesis.

involved and narcissistic (the unfortunate consequences of individualistic culture) if, in the act of mothering, the mandate is reversed. Perhaps we want to hold on to one of the last remaining elements of compassion, fellowship, and connection in a world where these values are fast diminishing. As Douglas & Michaels (2015:13) observe, ‘The new momism keeps us down by demanding so much of us, but keeps us morally superior because through it we defy a society so driven by greed and self-interest’. In this respect, through being a mother we are theoretically allowed to show and indeed revel in a softer essence to our characters, to let go of the constant battle to operate in terms of narcissistic efficiency as a measure of worth. The saintly status that accompanies visions of the ‘ideal mother’ is alluring, a seductive ambition. But I argue here that through media representations and overwhelming cultural imperatives to be seen to perform acts related to ‘good’ mothering we are highly encouraged to police both ourselves and others. This is where the characteristics of selflessness (highly prized in mothering ideology), and self-sufficiency dance around each other, always in tension. The notion of selflessness is deemed to be crucial to being a mother, as the cultural imperative is to always be giving of the mother's body, be it through providing safety in the uterus, providing milk as nutrition, and providing warmth and comfort *before taking care of one's own needs as a mother*. But in order to provide such attentive care, the mother actually needs to ensure that her own body is functioning at optimal levels and therefore will require her to place her needs before those of the baby's. The mother cannot win, in this sense. The notion of self-sufficiency, on the other hand, is a closed, self-contained one that seems to be at odds with the need to develop a relational bond with the baby. The concept of relationality reiterates that we are all embedded within social relationships, and psyche and society are always intertwined. To me, relationality is an open term, acknowledging, incorporating and building on the complexities of the relationships in which we are enveloped. Self-sufficiency, then, is at odds with the realities of mothering, as it seems to deny the complexities and importance of these relationships. Self-sufficiency conjures images of an inward-looking, somewhat hostile persona that is juxtaposed to the derivatives of mothering; and yet the ‘good’ neoliberal mother is supposed to occupy both of these positions. Independence in all mothering tasks is seen as fundamental in neoliberal, ableist mothering. This highlights the conceptual split - and the difficulties any mother experiences – between occupying the role of successful neoliberal citizen and a successful neoliberal mother. The theory of ableism can be used to expose this flaw in between these ideologies (‘good’ neoliberal citizen and ‘good’ mother) further, pointing out the impossibility of conflating the two without serious reflection on the meanings undergirding the values.

9.7 What can the study of ableism– the assumption of ablebodiedness – tell us about mothering?

The ideology of mothering in its dominant narrative appears to parallel neoliberal configurations of the ideal citizen, and at the same time reinforces and demands conventional depictions of women. Ableism infiltrates this idealised version; it is clearly and strictly articulated, and symbolised in explicit and covert ways. My research suggests that the ‘approved’ mother holds a number of valued characteristics: physical dexterity; fast pace; endless energy; emotional, mental and physical stability; and is self-contained, independent and autonomous. This leaves other ways of being to be downgraded from the ideal of mothering – kindness, love, support, tolerance, acceptance, interconnection and cooperation – aspects of mothering that I would argue are to be championed, and do not rely on ableist rankings.

There are a long list of ‘shoulds’, ‘always’s and ‘musts’ in the definition of a good mother that many women in the western world have absorbed from media, government slogans, healthcare paraphernalia and their social networks. As Arendell (2000) identifies, the ideology of intensive mothering has morphed the collective social and personal expectations of mothering from being a ‘good enough’ mother into being an ‘exceptional’ one (Green, 2015). It is not considered enough to be acceptable or satisfactory; mothers are pushed to be outstanding. This configuration of mothers is tied specifically to the excesses of ableism, pushing at its borders; to be exceptional, outstanding, and thus inherently *not* normal. The seduction of normativity loses its power here as the pressures of compulsory able-bodiedness spiral out of control.

Green (2015:199) points out the narrow parameters of intensive mothering. No matter the individual circumstances of the mother and the situations in which they parent, ‘the ideology of intensive mothering serves the interests of neo-liberal, white-supremacist, capitalist patriarchy. And it harms most people in the process’. By identifying and describing all other forms of mothering as ‘deviant’, this ideological ignorance reflects a wider inability to recognise the reality of motherhood for a great number of women. The form of intensive mothering that Hays goes on to explicate has become accepted as a given, as a natural set of ideas and assumptions about children and parenting. In this way, mothers are not consciously adhering to a set of ideologically informed practices, but operating in response to the objective needs of the vulnerable child. By positioning the child as always vulnerable and always the same, it denies the agency and the capacity of the child to adapt to individual circumstances, such as the skills of the parents to cater for their needs. For example, the child of a deaf mother may develop alternative signs to let the mother know s/he was in distress such as waving their

arms or showing visual signs of distress rather than audio-related ones. This also denies any reciprocity between the child and parent by constructing the child as an unchanging object in need of a set of concrete skills. This negates any flexibility and mutability involved in negotiating individual solutions to the unique interactions of the parent-child dyad.

Nevertheless, with reference to the book that I so readily dismissed earlier, perhaps mothering could be a path to re-capturing an enthusiasm for a world that is more focussed on the ideals of reciprocity and cooperation. For it is difficult to argue that the values and personal attributes shown in Figure 10 are not worthy *aspirations*. The point is, however, that these aspirations have morphed into directives, obligatory requirements that only serve to make most mothers feel like failures. For me, it is the relentless nature of mothering that is the hardest; trying to be an educator, a facilitator, a nutritionist, a nurse, a risk assessor, a playmate, a chief, a leader, an interpreter... the list is endless, and often on very little sleep - all at the same time.

It is important to remember, though, that this form of exhaustive motherhood is an ideology that it is possible (although rarely culturally *permissible*) to reject. Why, then, do many mothers conform to this ideal? If, as it is commonly stated, these ideals are impossible to achieve, why do we continue to uphold and aspire to them?

I however do not feel like I am able to fully reject this ideology; I feel somehow bound by it, strangled by its insistent demands, so much so that I have to battle to see alternative approaches. Perhaps this is because I subconsciously need to be seen as a viable, worthy citizen, however much it irks me that I am being so normative. This begs the question, 'why is the path to be seen as worthy so narrow?' But I lack the courage to forge a different path for myself and my child, to stick two metaphorical fingers up at society and say, 'No, I am doing it this way'. Dow (2016) remarks that a mother's immediate community networks have a great influence on expectations of mothering. I am part of a network of mothers, dubbed The Dream Team, made up of eleven women who became mothers at around the same time. We are all of a similar age; one is Danish-Australian, one is French but all others are from the UK. Two of the mothers would identify as Black, and I am mixed race. I am the only mother in the group who is disabled. We all have similar backgrounds, and all had been working (mostly as teachers or in the education field) prior to having a child, and all have returned to work after the maternity period. The philosophy and principles within this microcosm are distinctly 'child-focused' with definite adherences to attachment parenting styles creeping in to many of our discussions. I find myself trying - and, inevitably, failing - to live up to the ideals subliminally floated around by this group, wanting desperately to be able to (seemingly) effortlessly support/nurture/engage/teach/safeguard/protect - in short, mother - my child the way that they do. This accentuates the socially prescribed necessity of being self-contained; being capable of performing these act of mothering flawlessly without input from others. They seem to be able to put their children's needs first at all times. The jealousy that I feel in watching them do this indicates a focus on myself, something which is not permitted. I feel guilty for this on top of all my other

reasons for feeling guilty. Is this the seduction of normalcy? The desire to blend in, to emulate the 'norm'? Or is there something more at play here?

This excerpt accentuates the split between the cultural imperative to be self-contained and the imperative to be selfless that I introduced earlier. This, as Meyer & Milestone (2017:177) point out, 'embody(ies) the contradictions and difficulties of intensive parenting within neoliberal and postfeminist times'. The contradiction inherent in neoliberalism is that it purports to reject state interference in private affairs, preferring self-reliance and competitive entrepreneurship, but it does this by adopting an autocratic and dictatorial state which subliminally and coercively moulds citizens into a desired form. This can be seen most clearly in the cultural discourse around nuclear families, and the present imperative of intensive mothering.

9.8 The ideology of intensive mothering

Sharon Hays (1996) first coined the term 'intensive mothering' in her ground-breaking book 'The Cultural Contradictions of Motherhood'. Hays based her study on in-depth interviews with 38 mothers of 2-4 children (Hays, 1996: xii) along with a historical analysis of ideas about child-rearing and textual analysis of 'self-help' style books and articles aimed at offering 'expert' help and guidance to mothers. Armed with this data, she began to articulate the meaning of motherhood for many people in modern society. Although Hays (1996) recognises the dearth of adequate representation in her relatively small study sample, she believes that the prevailing concepts and interpretations indicated from her study hold true for many individuals who mother. Indeed, the often overwhelming cultural imperative to give, give and *give* of myself to my child, always and without respite, is almost guaranteed to make me feel like a failure. (It makes me feel incredibly guilty to admit that I sometimes wish for just one day off, a day where all I had to worry about was taking care of my own needs).

Hays elucidates the tension for mothers balancing commitments in the domestic sphere and in the working world, pointing out the two very different ideological traits - one of a selfless, nurturing, relationship-orientated mother and the other of a ruthless, selfish, ambitious career woman (Hays, 1996:3). Fiona Joy Green (2015), following Adrienne Rich, argues succinctly,

As an institution, motherhood encompasses a set of rules and regulations imposed upon and internalised by mothers (and others) that dictate not only how to mother but also who is a 'good mother' and who is a 'bad mother'. 'Good mothers', Rich observes, naturally possess 'maternal 'instinct' rather than intelligence, selflessness rather than self-realisation, relation to others rather than the creation of self'.

(Rich, 1995:42, cited in Green, 2015:198)

The struggle to incorporate these two personas is often left to the mother themselves, with countless feeling like failures in both roles. Many mothers, Hays argues, do not give up one set of commitments for the other; rather, they attempt to manage them both.

I feel pulled in two directions - both my roles require a substantial amount of dedication and commitment, and both are deserving of my full attention. My role as a researcher implores that I am on the ball, thinking clearly and sparkling insight into my work so that every sentence reads like something from a textbook. No, scratch that - it has to be imbued with originality, creativity, spark - something that enlivens the text so that it stands out and 'speaks' to the reader. This is totally deserving of my energy and assiduity, but then, but then.... when your small child has been awake all night, coughing and spluttering, desperate to stay asleep because she has had a long day at nursery (your fault, you put her in there for so long, you selfish witch), you take her to the doctors yet again but there's nothing you can do, just herbal medicine to soothe her poor throat and hope she sleeps better tonight... try and work through that fog of sleep deprivation and worry, and hope that something, anything that you're writing will make sense and touch the reader in some way. Because she holds the trump card; she must come before anything, no matter how committed you are to your work.

This paints a vivid picture of the intense confusion and anxiety arising from trying to pursue both worker and mother roles. In terms of the 'good mother' ideology I have absorbed. I construe myself as a 'selfish witch' for leaving my child in the care of others whilst I pursue my career. I am a failure in my role as a researcher as well, as my mind is not as focussed and sharp as my concept of the 'good researcher' tells me it should be. Ableism and neoliberalism conflate here in potentially damaging ways as conflicting impulses drive working mothers in opposite and competing ways. Ableism tells us that we need to be the absolute best that we can be in whatever we do. The forces of neoliberalism create risk in implying that you are expendable, and there are many others who would take your place if you are not quite up to the job. This feeling is echoed especially in the case of *disabled* motherhood. For therein lies the rub: disabled mothers often need to take care of their own needs first and foremost, before those of the child. I wish I had in the first few months, instead of feeling compelled to perform to ridiculous standards that are never achievable anyway. And, whilst I have argued that this is important – a well-rested, happy mother is more willing and proficient in ensuring that the needs of her child are catered for – this is outlawed in the dominant script of intensive mothering. Practices such as co-sleeping, baby-wearing, and feeding on demand, as we shall see, all require the mother to be at the baby's beck and call, and place the child's needs well before those of the mother's. In this way, the very form of disabled maternal embodiment is fundamentally prohibited.

The view of the child as innocent, vulnerable and constantly in need of protection is a concept that has been accepted as a hegemonic ‘truth’ since the early period of the 19th century (Nankano-Glenn et al., 1994). This brought with it the notion of the idealised, self-sacrificing mother who was devoted to this apparently all-consuming responsibility, and, as we have explored, she alone was to be charged with the care of the child. Douglas & Michaels (2004) author an accessible, persuasive book aimed at the layperson which explores the role of the media in perpetuating what they term ‘the mommy myth’:

Mothers are subjected to an onslaught of beatific imagery, romantic fantasies, self-righteous sermons, psychological warnings, terrifying movies about losing their children, even more terrifying news stories about abducted and abused children, and totally unrealistic advice about how to be the most perfect and revered mom in the whole country... Even mothers who deliberately avoid TV and magazines... have trouble escaping the standards of perfection, and the sense of threat, that the media ceaselessly atomise into the air we breathe.

Douglas & Michaels, 2004:3).

These authors go on to describe how these cumulative media representations reinforce, perpetuate and promote the insinuation that the only safe person to care for children is ‘mommy’. However, even ‘mommy’ does not escape this critical backlash; she needs to be constantly policing herself, driving down the narrow road of self-surveillance that leads only to Anxietyville and Shometown. According to Douglas & Michaels, through this media bombardment mothers were recruited as not only a captive audience, but also the main champions of the cause. By assiduously conforming to these narrow parameters, mothers themselves perpetuate the confines that they find themselves in, and the walls of this confinement get narrower and more specified as the standards of perfection are almost, but never quite, reached. This both supports and is supported by the plethora of products available on the market to educate, protect and improve one’s children. Baby Einstein toys, for example, that are meant to develop, stimulate and inspire a baby’s intellect are a must-have for the discerning mother. This assumes that the mother is intellectually adept and has a certain amount of disposable income. As Hays (1996:15) notes, ‘good’ mothering is ‘child-centred, expert guided, emotionally absorbing, labour intensive and financially expensive’. This limits the proportion of mothers that, in the limited and precarious dominant script, the label of ‘good’ mother can be applied to.

9.9 The Key Principles of Attachment Parenting

The central tenets of attachment parenting, at first glance, seem benign, obvious and as operating in the best interests of all involved. But if we take a closer look we can see the ‘normative shadows’ of ableism at work, lurking behind the scenes, almost invisibly guiding our movements like puppets in a play. Taken from the website, ‘Attachment Parenting International’ (<http://www.attachmentparenting.org/>), the eight principles are as follows;

1. *Prepare for pregnancy and birth emotionally and physically.* Taken at face value, this seems like a favourable, innocent directive, but if we look back on my experiences with accessing appropriate tools and resources, we can see the operation of discrimination (ableism in practice). This in turn created a wave of anxiety in me, which potentially harmed my growing baby. So far so good. Additionally, parents who follow these principles are highly encouraged to ‘continuously educate (themselves) about the stages of childhood’, encouraging mothers to measure their infant alongside developmental ‘norms’ and thus being co-opted to alert professionals to any sign of ‘deviancy’ in their own baby. This, in turn, would inevitably be blamed on the mother for doing too much of this, too little of that; in short, not being *good enough*.
2. *Feed with love and respect.* The ‘choice’ of bottle-feeding is given no credence here, and breastfeeding is seen as a must for proper nurture and development. The process of feeding on demand is heavily advocated and babies are encouraged, through proper guidance and attention, naturally, to know when they are full. The biopower in the fear of obesity starts young. The myth of healthy food ‘choices’ begins in infancy.
3. *Respond with sensitivity.* This directive outlines the necessity of being consistent, which is a nice idea but fairly impracticable. For mothers living with postnatal depression or chronic illnesses, being consistent may be difficult to maintain. Parents are encouraged to help their children ‘regulate their emotions’, to become placid, docile members of the neoliberal community.
4. *Use nurturing touch.* This instruction is about the need to physically touch, hug and hold your baby, which is clearly important but again this assumes an ‘able’ body. Baby-wearing, to provide loving warmth and security, is deemed essential in this affiliation. But baby-wearing, as my narrative shows, is only open to individuals who have the physical dexterity to attach the baby, or enlist in the aid of someone else to attach their baby to them (thus depleting the autonomy of the individual themselves).

5. *Ensure safe sleep, physically and emotionally.* Again, this appears to be an essential and benign directive. The advocates of attachment parenting strongly encourage bed-sharing, or at the very least co-sleeping. Co-sleeping, where the baby has their own sleep-space but the parent/s share a room, does seem to make sense for the safety of the child. But the parent's needs are not considered here, other than that they must be the same as the child's. Sleep-training must never even be considered, as this is tantamount to child abuse. This presumes that parents are robots who do not need sleep, or that one of them doesn't have to get up for (the limited description of) work the next morning.
6. *Provide consistent and loving care.* The website states, in echoes of (outdated and unworkable) psychologists' postulations, 'Babies and young children have an intense need for the physical presence of a consistent, loving, responsive *caregiver* (emphasis added). Note the singular caregiver, the cultural assumption being that it is the mother. This leaves absolutely no room for working parents. On the 'additional information' page for this commandment it states that day-care is allowed, but for no more than 20 hours per week. If the parent's working hours require more than that (which most do), a child under 30 months is in significant danger, unless care is provided in the home by a relative or trusted person. A solution to this, the API suggests, is for one parent to take the child into work with them. Of course, this would be very conducive to the parent's ability to focus, and to working relations. We have already attended briefly to the complexities in the notion of 'consistent'. In my case, consistency and patience have occasionally been difficult to maintain in a sleep-deprived state.
7. *Practice positive discipline.* The website implores, 'rather than reacting to the behaviour, discover the needs leading to the behaviour'. This assumes a level of cognitive awareness and 'emotional intelligence'.
8. *Strive for balance in your personal and family life.* This instruction assumes that the parent has the freedom and financial means to negotiate, for example, flexible or shorter working hours in order to 'balance' the desire and need to be with family against the realities of the cost of living. In general the kinds of families that the API appear to be aimed at are middle-to-upper class and probably nondisabled.

Attachment parenting is big business, involving a dizzying array of goods and services - such as breastfeeding pillows/pumps/supports, lactation consultants, birthing balls/pools, slings, books written by 'experts', - that are supposed to take the experience back to its 'natural' roots.

Entire industries profit from the promulgation of attachment parenting styles and natural parenting. These styles of parenting purport to adhere well with a feminist perspective, celebrating and enriching feminine characteristics - but in reality the principles of attachment parenting are essentially conservative and restrictive in nature. It ties the mother yet again to the domestic sphere, reducing them to the production ability (or not) of their 'uteruses, vaginas and breasts' (Tutuer 2016:6). We can see from the literature endorsing 'good' mothering standards that the valued woman's body is reproductively abundant (but not too abundant - 2.4 is enough, thank you), consistently healthy, and normatively productive. This, invoking Goodley (2014), is endlessly promoted in relation to the Other: the disabled, sick body. This, as we shall explore, is evidenced by the relative invisibility of disabled parents, and the non-recognition of their needs. The disabled parent is always present in the articulation of the 'good' parent, as a hidden referent of what not to be.

9.10 Attachment Parenting: logical solution or 'big business'?

Neoliberalism seeks to promote a particular kind of family, with interventionist policies targeting families it deems as 'problems', or in need of correction and they are mostly from the lower economic echelons (Meyer & Milestone, 2017). This is cleverly coupled with the notion that any responsible couple choosing to have a baby will of course want to provide what is best for the child. This means providing them with the best educational activities, the best nutrition, and the best schools and so on. Neoliberalism, in theory, ensures that these options are open to everyone, but as Meyer & Milestone (2017) point out, these 'options' are often reserved for the wealthy. Buying houses in the catchment areas of the (Ofsted reported) best schools is financially expensive and requires reliable wages from steady employment, something that in these uncertain times of austerity cannot be guaranteed. Again, parents are blamed for their failure to make the 'right' choices where children's lives are concerned, absolving the state (and the rampant inequalities caused by the captivation with neoliberalism) for their resulting poverty and disadvantage (Jensen & Tyler, 2012). The 'big business' of attachment parenting – involving the plethora of goods and services available on the market, arguably inspired by the postulations of psychotherapists writing nearly a hundred years ago – can be implicated in this. As Charlotte Faircloth (2010) states, mothers who adhere to this form of parenting are reflective of popular culture's acceptance of the literature surrounding attachment parenting style, and of the internalisation of this practice. It also reflects the broader societal infatuation with 'scientisation', a theme that was discussed in depth in the previous chapter.

However, theories do not arrive in a vacuum and it must be remembered that these psychoanalysts were writing from a particular epoch and their data had a very specific cultural, racial and class-specific bias. This fails to take into proper account the differing economic and social needs of a diverse array of women who mother, but these suppositions from esteemed psychologists are commonly held to signify ‘truths’, and therefore have a crucial bearing on the significance and supposed uniqueness of the mother-child relationship. We can see the ways in which the ideas from psychoanalysis are deployed and are used and reused to justify current neoliberal ableist regimes. By highlighting and reinforcing the mother-child relationship as the most crucial aspect in ensuring secure, rational, and stable mind-set in children, mothers have come to be seen as the solution – and cause – of all social problems, taking the focus well away from the rampant inequalities that neoliberalism promotes. Psychoanalytic theories are used to rationalise social and economic configurations, such as women mothering without state support, with the barely veiled insinuation that mothering is women’s responsibility alone, and if it all goes wrong then individual women, surely, are to blame. This is done by creating the illusion of choice, supported by the ‘new’ science (and eugenics) of epigenetics, the medicalisation of pregnancy and childbirth, and the ‘risk’ culture that surround it. The enduring nature of psychologist’s postulations has had a profound effect on women’s subordination and relegation to the private sphere, as Chodorow (1978:5) observed:

The early capitalist period in the United States produced an ideology of the ‘moral mother’: Bourgeois women were to act as both nurturant moral models to their children and as nurturing supporters and moral guides for husbands on their return from the immoral, competitive world of work. The ideology of the moral mother has lost some of its Victorian rigidity, but it has also spread throughout society. Women of all classes are now expected to nurture and support husbands in addition to providing them with food and a clean house.

Men’s and women’s roles, it is important to note, cannot and should not be said to be biologically determined; rather, they are manifestations that are socially, economically and historically created. By tying the enormity of the mother-child relationship onto the subsequent development of the child, psychologists exemplified the logic of working practices: that men go out to work and women stay at home and look after the children. ‘Parenting’ Chodorow goes on to say, ‘as an unpaid occupation outside the world of public power, entails lower status, less power, and less control of resources than paid work. Women’s mothering reinforces and perpetuates women’s relative powerlessness’ (Chodorow, 1978:31). Feminists have long pioneered many passionate debates concerning the growth in female participation in the labour

market (see for example Adkins, 1995; Folbre, 1995; Haraway, 2006; Young et al., 1981; Fraser, 2007). Despite this added encumbrance for women, the advance in women's representation in the public sphere has not been reflected in the way of public policy to provide childcare or flexible working hours to accommodate what is still largely seen as women's responsibilities - i.e., childcare (Johnston & Swanson, 2006).

The contexts in which women mother are inherently socially constructed, historically distinct and steeped in moral values and social practices. Esteemed psychologists such as Freud, Winnicott and Bowlby would have us believe that motherhood is a singular, universal phenomenon and yet it is everywhere an individual experience that is indelibly marked and influenced by a vast array of factors. By reinforcing the cultural imperative towards how a 'good' mother should be and act, it can be argued that this is a stealthy means of reproducing ableist and oppressive regimes. Through the governance of the mother – strict guidelines on what she can do and what she can be – society has succeeded in reproducing a narrow acceptance of mothering behaviour, one that gives little room for inclusion.

In this chapter we have seen that the theoretical tools that can be devised to articulate ableism can also be used in its perpetuation. We have discussed the intricate relationship between the imperatives of 'good' mothering and being a 'good' neoliberal citizen, and the similarities and tensions between the two. We have discovered that directives for 'good' mothering actually exclude most people, and consistently fail to take into account the social position of the mothers. The insinuation is that for mothering to be done adequately, it requires the full, undivided attention of the mother which precludes working mothers. Mothering is financially expensive, requiring investment in all manner of toys, books and activities. In this way, the ideology of motherhood is class-based and exclusionary. This also has the consequence of supporting a market-based society, with parents being encouraged to, for example, buy expensive homes within the catchment areas of the 'best performing' schools, or else limit your child to a life of drudgery and struggle. This in itself is predicated on the myth of 'choice' - that the choices a parent makes in their lifestyles will determine their children's fate. This conveniently ignores the impact of poverty and inequality, driven by government decisions, and the impact of this inequality on the lives of citizens. This chapter has also tried to articulate both the ableism and disablism inherent in these mandates of motherhood, highlighting the difficulties of addressing the mother's own needs as a disabled person whilst adhering to the dominant script of mothering ideology. I have tried to outline the danger in assuming that every

mother is able-bodied and able-minded, and to express the restrictive oppression that results from this. Using my experiences as an example, I have tried to narrate the dangers implicit in mother's pushing themselves to their limits which can have effects on their health and mental well-being.

In the final chapter of this project, I will be expounding on the invisibility of disability in motherhood and the potential consequences of this, and also celebrating the ways in which disabled mothers defy and resist the script that both outlaws and ignores their existence.

CHAPTER TEN: BREAKING THE SPELL

10.1 Overview

This chapter will review the key points made in Chapters Eight and Nine, and reflect on the implications of these to the interrogation of ableism in motherhood. Allow me to advise the reader to pause here, reflect on the information gathered, and I will re-equate you with the initial research questions: ‘what *is* it that is valued in motherhood?’ ‘How do we as a society uphold and reinforce these values?’ And, perhaps the most important question, ‘how can the critical study of ableism, in conjunction with a critical social psychoanalytic and post conventionalist approach, be used first to expose then to challenge and break down these stifling structures in order to forge a path for more imaginative, creative parenting practices?’. I shall also discuss the ways in which the theoretical tools that I have chosen have aided the interrogation of ableism, and have been used to shed light on the position of disabled mothers in society.

I hope I began to stimulate some responses to the first two questions in Chapters Eight and Nine (which I shall review briefly now), and so the final section of the chapter will be given over to addressing the third theme, which is around the ways in which disabled mothering practices are creative and innovative, and draw on instead of refuting reciprocity. As such, this chapter will introduce some of the creative and innovative ways in which disabled women have agitated and resisted the systems of ableism that dictate that they are not as worthy as non-disabled mothers. As my narrative has attempted to show in the last two chapters, the questioning of the dominant script of motherhood often takes an inordinate amount of courage and infallible determination. This means that the path of resistance is often littered with obstacles, setbacks and crises of faith. Through mine and other’s narratives I will underscore the effect that the degradation, surveillance and humiliation of others, even in the tiniest of ways, can have on the self-esteem of mothers, resulting sometimes in poorer performance. With the (I perceive) critical gaze of the public on me, I often lose my confidence in performing mothering tasks. That being said, though, strangers can often turn out to be an incredible source of support particularly when I frequent the same supermarkets or parks, helping to pack my shopping or to strap my squirming toddler back in to the buggy. The ease with which disabled mothers are able to ask for help will be seen with the acceptance of different ways of doing motherhood, but I argue here that first we need to recognise the plethora of tacit ways in which ableism is performed. Only by first exposing this can the collective genealogies of the public,

product developers and government officials be mobilised to make changes that include, as opposed to preclude, all forms of embodiment and capacities. In order to do this, I will look at ableism as an epistemology, and reflect on the implications this has for disabled mothers. I will then begin to tease out the ways in which disabled mothers have been oppressed by struggling to conform to the narrow cultural imperatives of motherhood and also the means by which they have found other, more realistic interdependent methods of performing mothering. I believe there is a danger in finding adaptive supports purely so that disabled mothers can ‘do’ motherhood in the same (narrow and restrictive) way that non-disabled mothers do *without challenging the narrowness and restrictiveness of these ways in the first place*. I shall expand upon this point in more detail in this chapter. The discovering of new and innovative methods is where the application of postconventional perspectives will shine their visionary light, exploring the practices and processes that disabled mothers use to enrich their parenting styles.

10.2 Summary of Chapters Eight and Nine

In Chapter Eight I explored the idea that social media and popular media such as guidebooks, healthcare paraphernalia and newspaper and magazine articles have been co-opted in producing and perpetuating the idea that the mother-child bond is sacrosanct, and to be held accountable for a host of social ills. This blends in and hides behind the promotion of neoliberal ableism. It necessitates that individual mothers take prime responsibility for their lot in life, additionally heaping this responsibility with that of their child/ren. I have described how the forces of biopower in every guise imaginable are inflicted onto the pregnant woman, effectively blaming her for anything that goes wrong in the pregnancy. The notion of ‘choice’ is heightened here, as the wrong choice (of genetic partner, of exercise, of food, of screening tests, of lifestyle, of income...) is inevitably blamed on the individual woman, and held to be the reason for whatever situation she finds herself in. The rampant inequalities caused by neoliberalism are vastly negated here. Ableist tendencies seep into all of these processes, but do so in such a way that the seepage is almost invisible and highly naturalised. The search for genetic anomalies in the foetus, for example, is presented as being in the best interests to all involved, and the infallible trust in the advice of experts is seen as unquestionable. Ableism in matters of pregnancy and motherhood is everywhere, seen most strongly in the normative spatial arrangements of hospitals and playgrounds, and the quite literal message taken on board by disabled mothers is ‘these things are not made for you’. This is exacerbated by the lack of provision for disabled mothers in the consumer market, a lack that can heighten the anxiety surrounding pregnancy and early mothering experiences as I have tried to show in my use of

autoethnographical data. This is the way that society – however innocently – reinforces and perpetuates limited ideas of who can, and who should, mother. The wide cultural acceptance of the postulations of psychologists has been politically manipulated to mesh well with the favoured neoliberal citizen, with the characteristics of self-reliance, self-mastery and self-discipline dominating the ideological landscape. These traits are echoed in the depiction of the ideal mother.

In Chapter Nine I reflected upon the psychologisation of mothering ideology, and the ways in which this phenomenon could be used both to inform the interrogation of ableism in motherhood, and to be implicated in its perpetuation. The continued cultural authority given to postulations of psychoanalysts such as Freud, Klein, Bowlby and Winnicott, and the interpretation and reinterpretation of their theories have arguably been of great disservice to the majority of individuals who mother. The interpretation of their theories has served to imbue the mother-child bond with such a heavy significance that it masks and obliterates other essential factors such as poverty, social circumstances or the attention needed for other siblings. This is unfair to all involved, as it leaves no space for the role of fathers, has unreasonable expectations for mothers, and fails to take into account the plethora of other responsibilities a mother may have.

The cultural infatuation with intensive mothering practices, such as bed sharing, (breast)feeding on demand, and babywearing all assume an able maternal body. A disabled mother may have needs that preclude bed sharing, or may not have the physical resources to breastfeed. I had many difficulties: with the positioning of my baby whilst breastfeeding, my arm(s) faltering especially over long periods of time; with swapping sides; and with feeding in public places with no pillows to support her body – teamed with the stares from strangers that I perceived I was getting. The cultural pressure to perform these acts, as we have seen, is supported by scientific ‘evidence’ that imbues their authority with almost impenetrable ‘truth’ claims. The decision not to perform these rituals is presented as selfish, irresponsible and the actions of an unfit mother. I have tried to use a critical approach to social psychoanalysis to help me tease out the implications of the hegemonic psychologisation of motherhood for disabled mothers, alongside the critical study of ableism that runs throughout this thesis.

10.3 What has my application of critical social psychoanalysis and SiA told us so far about the position of disabled mothers in society?

I made use of critical social psychoanalysis in my arguments that only certain kinds of (non-disabled) mothers are permissible in the ideology of motherhood (namely: middle-class, white, heterosexual, and married), and certain kinds of sentiency are promoted. This includes: physical dexterity, energetic, emotionally/physically/mentally stable, independent and autonomous. This leaves other ways of being to be downgraded in the articulation of the ideal mother. The obsession with the autonomous performance of ‘mothering’ duties is potentially harmful to all involved with the child’s life. Fathers or significant others who may wish to perform these duties may be discouraged from doing so due to the cultural imaginary that it is the mothers realm, and may not wish to interfere. This perspective is also damaging to mothers – particularly disabled mothers – who may need assistance in these tasks. I have to keep reminding myself, despite all the theoretical tools that I am now armed with, that the fact that I need assistance with these tasks *does not make me any less of a mother*. This shows quite how entrenched the sticky residue of ableism is. Even theorists who should know better than to venture into this hierarchical valuing system still manage to get snared in its trap.

I also made use of this analytical framework to give theoretical voice to my feelings of shame and internalised ableism that are central to developing an understanding of the effects of compulsory able-bodied motherhood. In Dan Goodley’s (2012:181) words, ‘oppression is felt both psychically, subjectively and emotionally but is always socially, culturally, politically and economically produced’. It is in sometimes minor ways that oppression takes its toll, but it is the build-up of these microaggressions that have a cumulative effect on the psyche of the disabled individual. But, as Goodley (2012) suggests, psychoanalysis must be turned around to focus instead on the psyches of non-disabled people to investigate why they wish to denigrate a whole group of people in this way. I hope I have begun to explore this crucial question throughout this piece, and will draw on Goodley (2012) and Wilton (2003) to re-emphasise this point.

Wilton (2003) engages the psychoanalytical theory of castration, (particularly as reformulated by Lacan) to identify and explain the unconscious equation of disability and lack. In this conception, disability is strongly associated with the frailty of the human body, something which the abled imaginary cannot concede with; ‘an ultimate inability to maintain control over the physicality of our bodies represents an important source of anxiety’ (Wilton, 2003:371). This equates disability with tragic loss, akin to the medical model of disability, wherein it is

seen as natural for the non-disabled to react to disability with pity or horror (Wilton, 2003:374). Indeed, 'Freud's castration complex, a key component of psychoanalytic theory, describes, and at the same time is implicated in, the positioning of physical disability as a naturalized other' (Wilton, 2003:376). Into this analysis, we can bring the burgeoning fascination with bioethics which seeks to establish genetic 'norms' to which disability can be compared (Leach-Scully, 2005). This growing ableist trend enhances the binary division of abnormal/normal that social-model thinking has worked so hard to dispel. The Lacanian reformulation of the castration complex re-inscribes the importance of the socio-cultural construction of disability. In Lacanian theory, we are all constructed as suffering loss from the very start, through the symbolic loss of the (m)other. We seek to disavow this loss by projecting all favourable attributes onto the illusory body of the able (read: strong, perfected, infallible) (Wilton, 2003:380). In other words, 'The supposed integrity of the able-body...is sustained by the localization of the lack in the body of an-Other' (Wilton, 2003:381). This theory of projection is helpful to describing a possible reason for non-disabled people's unconscious reaction to disability, and thus is helpful to an analysis of ableism in this realm.

Disabled people hold space in the cultural imaginary for the projection of 'lack' – in psychoanalytic terms, the fear and uncertainty around embodiment that the psyche of the non-disabled world is unable to recognise or to hold within themselves, is thrust outwards onto the bodies of disabled people. This fear of uncertainty and vulnerability is denied in the bodies of the non-disabled. Critical social psychoanalytic theories suggest that this may be one of the reasons particularity, and the embodiment of particularity in disabled people, is so rejected. Psychological theory can be mobilised to link the ideological formations of capitalism, neoliberalism and ableism in that they share a particular view of the 'productive', and thus hegemonically valued, body. This is where the critical study of ableism and critical social psychoanalytical theory inform and enliven each other, and the tedious need of compulsory able-bodiedness to occupy a state of conformity can thus be interrogated. Paradoxically, this need to blend in with ever-changing standards of normalcy agitate the neoliberal ideals of competitive perfection. This is one of the many contradictions I have attempted to expose in this project.

I have endeavoured to apply an ableist lens to the seduction and reverence of normalcy, especially in relation to disabled motherhood. This is intricately tied to the power of ableism in rendering disability both profoundly visible (in the case of genetic screening) and invisible (in the case of disabled mothering). Not catering for disabled mothers, as my narrative

illustrates, provokes anxiety, reinforcing the evaluation of disability as lack and potentially perpetuating internalised oppression. I have also tried to tease out the links and contradictions between conceptions of the good neoliberal citizen and the good mother, revealing a narrow fraction of women deemed permissible to mother. My overall aim in Project Two was to articulate how the study of ableism can be used to shed light on the practices and procedures of mothering ideology, and I hope it has served this purpose. The next section of this chapter will focus on the trials and tribulations - and successes and victories - of disabled mothering.

10.4 Unmasking ableist actions

Studies (Walsh-Gallagher, Sinclair, & McConkey 2011; Lawler, Begley & Lalor, 2015; Skinner, 2011; Lappetelainen, Sevon & Vehkakoski, 2017; Prilleltensky, 2004; Thomas, 1997; Malacrida, 2009), have shown that there is often a positive ontological reframing when a disabled woman transitions into motherhood. Her new-found status as a valuable mother, blossoming life into this world, often symbolises a fresh change for women previously categorised as little more than a drain on the system. Lappetelainen et al., (2017) found that the experience of motherhood allowed women to define themselves as mothers (and therefore women) first, and disabled second. The women in their study found that a sense of empowerment and pride accompanied their decision to become a mother, and motherhood was an integral part of the subject's womanhood (Lappetelainen et al., 2017:146). However, there lurks beneath this view a stranglehold of normalcy when the disabled mother fights against all odds to be, or to be seen to be, the Perfect (Self-Contained) Mother. (We will return to the 'self-contained' aspect of this statement at a later stage of this chapter, as this in itself is worth unpacking). Nevertheless, these studies show that many disabled mothers feel unabashed pride at becoming a mother and feel that this is their chance to show their worth. For some disabled mothers, according to a study in the *Journal of Advanced Nursing* by Lawler, Begley and Lalor (2015), the transition to motherhood caused them to 'take stock', so to speak, to recognise what is important to them by letting go of caring about other people's opinions of them. The process of becoming a mother, as reported by the authors of the study, was '... a period of intense personal growth and self-definition, change and transformation, one that afforded them a sense of belonging to and acceptance by a society that heretofore women felt shunned people with a disability' (Lawler et al., 2015:1679). It is interesting to note, however, that these mothers only began to feel a sense of self-belief, autonomy and mastery *after* they left the hospital grounds, where they were freed from the critical surveillance of the clinicians. This points to the damaging effect that 'professional' scepticism can have on the self-worth, and resulting

feelings of ability, of the mother. If the mother feels constantly undermined, degraded and humiliated, the consequences upon her self-esteem can be devastating. This form of psycho-emotional disablism (Reeve, 2012) is cruel and exhausting, and is a colossal drain on the limited energy resources of any new mother.

I am fundamentally drained by the amount of stares and patronising 'advice' literally hurled at me from complete strangers in the street. 'You need to pick her up, poor thing – it's obvious she needs a hug', or 'She's hungry, anyone can see that!' But when I do clumsily attempt to pick her up, they say, 'What are you doing? You're hurting her! Stupid girl!' I can see them taking in my embodied 'lack', using it to injure and re-injure me. I am forced to be a prisoner in my own home, scared to go out unless I am accompanied by an able-bodied person who can pass me the baby if she needs comforting or feeding or whatever. I daren't go out on my own with my baby in case she fusses and people judge me harshly. And yet I know that this isn't being fair to her – she needs fresh air and trips to the park to stimulate her senses... but I just can't face it. I am a horrible mother, and my baby deserves so much better. I'm being selfish, yet again, putting my own needs before hers. But every trip out leaves me feeling so humiliated....

In my experience, as this narrative shows, this has led to me feeling that I am unequivocally unable to cope with the responsibilities of motherhood, and therefore unable to reliably handle my own child, as I have tried to illustrate in my use of autoethnographical data. I feel the grip of this sensation starting to weaken as I explore and expose the ableism tied up in constructions of mothering that emphasise the physical dexterity of mothers. Additionally, a postconventional perspective would gently encourage me to throw away the 'rule book' and devise alternative ways in which to retrieve my baby from her pram which may involve help from others or the adopting of peculiar positions - thinking outside the box.

In their report in the journal *Midwifery*, Walsh-Gallagher et al. found that the disabled women in their study welcomed pregnancy 'as affirming their identity as women and as mothers' (Walsh-Gallagher et al., 2012:156), despite the reactions from professionals. The women felt joyful at the news of their pregnancy, and felt that this had given them a sense of achievement and purpose, that their previous status as just 'disabled' was, partially at least, eradicated by their new-found status as 'mum'. But in this study, however innocently, the researchers show their ableist bias. They propose strategies to ensure that disabled mothers-to-be are afforded the same rights, respect and dignity as non-disabled mothers, which involve training medical staff in disability awareness; offering more support to disabled mothers, thereby reducing their fear that their child will be removed from them; and involving these mothers in discussions about the decision-making process of their own pregnancy and subsequent children. These

measures seem profoundly obvious, and many would assume that they would without a doubt be offered to all citizens of a democratic country, but when it comes to *disabled mothers* these researchers deem it necessary to point out explicitly that this should be the case. These remarks are treated as ground-breaking, as innovative ‘suggestions’ that the medical staff can choose whether or not to take on board. To me this is indisputable evidence of ableism within pregnancy and motherhood. By offering the necessity to treat all mothers with respect and dignity as a *suggestion* when it comes to disabled women, these authors bely their ableist stance and reinforce the position of disabled people as second-class citizens. There should be no question of their being consulted on the status of their own pregnancy and subsequent children, or their custodial rights.

However temporarily uplifting and empowering these narratives of choosing motherhood are, many more studies show that the experience of pregnancy and early mothering for disabled women is treacherous, requiring inordinate amounts of iron will and determination. The emotional labour of acting in defiance of family, friend and professionals is a crucial factor threatening to obscure and dampen the transition to motherhood for many disabled women. Researching the phenomena of disabled mothering has shown me that I am unfortunately not alone in the hostile responses from the medical profession. Studies of disabled pregnant mothers-to-be confounded this perception (see Crow, 2003; Lawler et al., 2015; Thomas, 1997; Prilleltensky, 2004; Skinner, 2011; and O’Toole, 2002). All of these studies show that disabled women are routinely objectified, marginalised, and treated with a toxic mixture of scorn, disbelief and distaste. Often disabled mothers are seen as selfish and reckless for bringing a life into this world when it is a common misconception that they can barely look after themselves, however true or false that might be. The ‘normal’s’ (Goodley, 2014) fear of impairment drives medical screening practices, with the assumption that if the foetus is found to be ‘flawed’ or ‘abnormal’ in some way then it would automatically be aborted for suspicion that this life would potentially be another burden on the system. (For more on the ethics and justifications for prenatal screening, see especially Gagen & Bishop, 2007; Wasserman & Asch, 2006; and Yurkiewitz et al., 2014). This calls into question the very existence of disabled people, and defines their lives as, at best, troublesome. Moreover, studies (Kirshbaum & Olkin, 2002; Parish, 2002) have shown that there is a concern amongst the nondisabled world about the disabled mother’s ability to mother well (Walsh-Gallagher et al., 2012). It is entirely plausible that some disabled mothers, like me for example, share this concern, but if we were provided, *as a basic right*, with appropriate tools and services then this ‘concern’ would be less of an

issue. As Liz Crow (2003:3) states in her presentation to the Department of Health around the provision of maternity services to disabled women;

When I'm on the outside needing to get in, what I see is a lot of people missing the point. My being on the outside is not about me, but about them. It's about the assumptions, and the ways of working that exclude whole groups of people. Tackling that exclusion, by introducing inclusive practice, is not about making 'exceptions' or meeting 'special needs'. (*It is only when they are not provided for that needs become special*). In maternity services, inclusion is about achieving a start where I can primarily be *pregnant* – not because I am the same as non-disabled pregnant women but because my needs are just as integral to planning and working practice as theirs. (Italics added).

I feel it is startling that the needs of disabled women are routinely not taken into account. Crow's point here is that, as a disabled woman, she is largely not provided for in maternity services and thus rendered invisible, but as soon as she alerts her presence to them, she becomes a 'problem' in need of 'special' needs. In her own words, she becomes 'centre stage' (Crow, 2003:3). We can apply her statement, 'it is only when they are not provided for that needs become special' to a range of institutions and social practices, and it has specific salience here. If society was open to the diverse range of people, not just women, who mother (in the broad sense of the term) I may have felt more secure of my impending motherhood as the range of adaptive solutions and the resources available to me may have been more readily accessible. The story of disabled women not being provided for, or being begrudgingly provided for with the label of 'special needs', is painfully echoed throughout all of the literature I have engaged with. The compulsoriness of able-bodiedness is starkly reflected here in the complete lack of provision for *differential* embodiment. We can see the infection of ableism seeping in to the minds of all involved with the planning of maternity services, starting from beyond the uterus with the new epigenetics, and continuing in its destructive path towards the delivery room and beyond. This demonstrates emphatically the sense of ordinariness, the taken-for-granted way in which ableism is performed without the perpetrators even realising it. This is one of the aims of this thesis - to clearly articulate the nuanced ways in which ableism is enacted. The realisation that these seemingly inconsequential microaggressions cumulate into wider acts of social oppression that cause harm to a myriad of people will hopefully generate action on the part of government officials, town planners and, steadily, the general population.

Sadly, as it presently stands, disabled women are not on the list of society's idea of 'good' mother material. The dominant narrative around disabled women, and disabled people more widely, is that they are asexual and dependent, and therefore inherently incapable of being care *providers*. This is a stark reminder that reproductive liberty does not have the same significance

for every woman. And yes, there are indeed concerns about the impact that a loss or malfunction of a limb or energy fluctuations has on a person's ability to mother, as my narrative shows, but how much of this is due to practical concerns (which in a truly inclusive society would be provided for) and how much can be attributed to internalised ableism? If disabled mothers – like me – continue to absorb negative depictions of themselves and their capabilities or think that the only way of succeeding in the mothering role is to emulate ableist norms (to the possible detriment of their physical and mental health), we will succeed only in perpetuating the status quo. Many studies have made clear that disabled women are treated as outsiders in the world of mothering. We are, to put it mildly, discouraged from entering this sacred hallow.

10.5 Ableism as epistemology of motherhood and the consequences for disabled mothers

The unattainable standards of current mothering ideology are an issue for all mothers, not just disabled mothers. Note that I defined mothers as those who engage in the act of mothering, not just biological mothers or even just women. This is important because through an ableism lens, we can see just how far and wide the destructive elements of ableism can be. Consistently judging oneself on standards that keep increasing as we as a society get nearer to them, putting them as always and inevitably beyond our reach, negatively affects the psycho-emotional self-regard of all of us. This is the dizzying reach of ableism; it delves in and holds the power to strangle each and every act we perform, but does it in a way that is so stealthy that it almost passes by unnoticed. If we see ableism as an epistemology of the modern world, we can see that disability discrimination is a consequence of ableism; of holding up the mythical perfected body and comparing ill or impaired bodies to it. Even if disability discrimination did not exist, the structures of ableism and their flaunting promulgation in the media, signify that I would constantly be encouraged to compare myself against the mythical able-bodied ideal, and found wanting. This endorses a very narrow, limited version of what a valued and 'successful' mother looks like. 'Successful' mothers are touted as being active, independent, autonomous, rational, masters of their own body, dexterous, educated, physically and emotionally stable and endlessly energetic. But I have found that the only thing that is actually necessary is to love and support your child. That's it.

10.6 Why does disablism happen? What is it that 'the normals' are scared of?

Why is it, then, that non-disabled society frowns upon, and often actively discourages disabled mothering? On the surface opponents to disabled mothering argue that the mother (inevitably) could not cope with the demands of childrearing, and that there is a fear that the 'biological

defects' could be transmitted to the child. This, they say, would constitute irresponsible mothering. But I sense there is something deeper at play here. I argue that by admitting us in to the sacred hallow of motherhood, this threatens to destabilise the social construction of disability as inherently less than, ineffective, *invalid*. The Mother is an esteemed figure in society, and conflating the two stereotypes further weakens the precarious binary. It engenders a deep-seated anxiety in 'those who are able to broadly align themselves with the illusory standards of the psychosocial imaginary' (Shildrick, 2012:32). Invoking Wilton (2003:381), by refusing to conform to the stereotypical depictions of disabled women being asexual and therefore incapable of reproducing, disabled mothers embody a 'lack of support of the lack'. Their very existence serves as a reminder of the instability of the social order that wishes to repel disabled bodies. Sadly the line is redrawn again and again through lack of access to social spaces and invisibility in the consumer market.

Disabled motherhood creates fear because it exposes the instability and the futility of aspects of neoliberalism and the incessant race for perfection that it is grounded upon. This exposes as futile the hundreds of products on the market aimed at 'making you a better person, inside and out'. It does this by dispelling the assumption of the relegated Other - the disabled - to which able-bodied society can compare themselves and feel relieved. I would go as far as to say that through disabled motherhood, we can actually see the frailty of all mothers, exposing the difficulties and tenuous pleasures of their lives.

As my narrative has hoped to illustrate it takes copious amounts of energy to resist the dominant script of motherhood, to arm oneself against the bombardment of 'essential' information, warnings and advice - often well-meaning - directed at the mother from pre-pregnancy onwards. This, as I have hoped to show in these chapters, can create significant feelings of inadequacy that can and, as my narrative has shown, does negatively affect a person's ability to mother. Negative expectations can bring about negative realities, and can encourage disabled mothers to become complicit in perpetuating the ableist ideal of the Perfect Mother.

Internalised psycho-emotional ableism (Reeve, 2014) leads me to think and feel that am not and never will be as good as an able-bodied mother. I have to face the fact that I will not be able to dress my child the way that other mothers do... but so what? Already I can see that she wants to start doing those things by herself anyway. Maybe by tying my role to my physical 'usefulness' to her, when she can dress herself and no longer needs me to help her, I would feel a similar wrench - feeling like I was disposable - that I did when I stopped breastfeeding. Perhaps a more useful thing to align myself with in relation to her needs is more intangible... the love, support and connection that being her mother brings.

10.7 Antagonising ableism, disputing disability: Postconventional futurities

How can mothering be done differently in a way that celebrates, instead of limiting, disabled women? One of the main justifications for the disablism mother's face is the taken-for-granted assumption that disabled women are inherently incapable of being mothers. This blatant discrimination is often touted as being either in the mother's 'best interests', or as a preventative measure in order to protect the vulnerable child from the inevitable damage done by maternal disability. However many stories exist that counter this negative assumption. For example, Karen Blackford (1999; 1993a; 1993b 1990; 1988) has written extensively on the experiences of disabled mothers, and has carefully identified the strengths that parenting whilst disabled can bring. In her 1999 article for the journal *Disability and Society*, she focuses on a child's ability to construct and negotiate new meanings within social relationships - and to formulate new notions of normality and disability. Postconventionalist theories help to argue that many mothers are disabled by *the lack of insight and awareness* of, for example, architects and product designers in the mass market that *fail to recognise our existence*. Thus, by disabled women having and keeping their children, perhaps we can begin to transform the social world. Society created the negative connotations associated with disability, and lack of foresight created structures and institutions that are inaccessible to a range of people, not just wheelchair users. By forging respect and awareness of disability through the experiences of children being parented by disabled mothers, we can begin to spread an increasing recognition of the creativity and resourcefulness of disabled parenting. The children themselves may be helped to become innovative, imaginative citizens who will be more responsive, kind and tolerant in building the world of the future. Following Susan Wendell's (1988) call for the unique knowledge of disabled individuals to be counted and celebrated, we come to see the possibilities engendered from disabled parenting. Furthermore, Blackford (1999) recognises the possible positive outcomes on children: that they have a positive perception of accessibility equipment; coping in the face of uncertainty; learning responsibility by helping with household responsibilities; being more caring and learning how to care for others; and engendering a sense that we are connected to our bodies. The insinuation that independence while mothering is a necessity needs to be discarded as it can create feelings of shame in disabled mothers if they need to ask for assistance. Disabled mothering allows mothers to teach perseverance and determination, but also to allow being overwhelmed by feelings of inadequacy, helplessness and despair - partly induced by society's belittling expectations, and partly due to the impairments and impairment effects. Disabled mothers persevere in a world that wasn't designed for them,

learning creative strategies and adaptations, creating knowledges that are not available to the non-disabled world. We need to harness this power and celebrate it. We need to focus on the strengths engendered in disabled motherhood but we also need to be honest about our experiences of motherhood, warts and all. By being honest we can share in our realities, acknowledging and honouring them for what any difficulties encountered can tell us about society and its values, illuminating different possibilities for disabled mothering practices. Disabled mothers need to refrain from reinforcing and perpetuating ableist ideals of motherhood, and start paving the way for diverse parenting practices to take place that appreciate and value different forms of embodiment. Through interdisciplinary practice, we can learn from other Others. The skills of using kinship support as an adaptive strategy - using the support of grandparents, aunts/uncles, sisters and brothers, friends and others in one's social network - to assist in the care of the child is one pertinent example. Allowing mothers to enlist in the support of others, to be *interdependent*, instead of demanding immediate mastery of mothering skills would be a step in the right direction. This approach could be termed 'relational' - using the skills and experience of other people, providing employment and fostering interconnection. This would enrich the child's environment, introducing them to many new experiences and expanding their worlds. Mothers could remain central, Blackford (1999) writes, to their children's lives by, for example, orchestrating the help that others provide, and by interacting with the child whilst the help is given. In this light, the mother is maintaining responsibility for ensuring that all of the physical needs of the child are met. Following this proposition, though, does little to revert the insinuation that these actions are the mothers' responsibility; nevertheless this can conserve vital energy for love and support. However, there are flaws in using the approach of relational mothering, as I am experiencing now. Finding appropriate help is difficult, but having a database of affordable help would be a solution to this, not just for disabled mothers but for all. Additionally, accessible and affordable day-care would ease some working parent's concerns, as would active engagement among employers with flexible working hours and conditions. This could have potential benefits to society as a whole as parents could be more committed, more efficient workers knowing that their domestic life was taken care of. Furthermore, an active and committed engagement with points raised from disability politics - such as the need to recognise the individual needs of workers and to provide any necessary accommodations to allow them to work (i.e., adjustments to the building, flexible working hours etc.) would be beneficial for all employees and may actually increase production levels. These clearly are not new, innovative suggestions but their operation in practice still appears to be in its infancy.

I have endeavoured to apply a mix of critical social psychoanalysis, studies in ableism and postconventional approaches to the analysis of my stories in order to develop a more productive account of my experiences. I have felt a certain catharsis in the telling of these stories, as well as re-experiencing the pain and anguish that these events caused me, but I wanted something constructive to be gained from my struggles. My take on postconventional perspectives is that they seek to enhance and strengthen ideas that are uncommon and divergent, and encourage creative thinking. These approaches recognise and appreciate the unfinishedness, the contingent, the ethereal, and do not seek to place people into wholly this or wholly that. As such, these are approaches that can be used to celebrate the interdependent nature of disabled mothering, and to venerate the plethora of ways that disabled women perform these tasks.

I have argued in these chapters that society caters for a limited percentage of mothers, and that the ideology of motherhood rests on an assumption that mothers are able-bodied and able-minded. This is damaging to all mothers, and women who are contemplating motherhood. Through a critical social psychoanalytic lens, I have taken the reader through the postulations of ‘esteemed’ psychotherapists and child experts, in order to reflect on the ramifications of these thinkers on the child-rearing advice and judgement bombarded at mothers from pre-pregnancy onwards. Then I made use of the critical study of ableism to articulate the ideals associated with being an ideal mother, and reflected on the impossibility of these demands. I have also invoked both of these critical theories to probe the implications of the new fascination with neuroscience and the effect that biopower has on pregnant women. These chapters suggested some possibilities for understanding the power of ableist discourses, as I feel that this is one of the keys we can use to understand the roots of disability oppression. Finally I, like many other disabled mothers (Fritsch, 2017; Prilleltensky, 2004; Blackford, 1988; 1990; 1993a; 1993b; 1999; Skinner, 2011; Crow, 2003) have tried to identify the strengths that disabled mothering engenders and have underscored the importance of celebrating the unique knowledge that this can bring, whilst also being mindful not to ignore or suppress opportunities for disabled mothers to speak out about the difficulties they experience mothering in a society that assumes, and demands, able bodiedness.

But the danger is that, as with the traditional ‘social model’ mentality, the urge to perform disabled mothering ‘just as well, if not better’ than able-bodied mothering *provided disabled mothers have the necessary accommodations*, threatens to miss the point entirely. Rather than berate ourselves for failing to live up to an impossible ideal, we need to interrogate the value systems that underpin this oppressive ideology. We need to map out our own terrain, create our

own paths that draw on, instead of denying, the inevitable interconnectedness of all of us. Postconventionalist theories, in querying the applicability of the bounded, rational, distinct self to today's complex world, insinuate that the 'ideal neoliberal citizen' is actually an outdated concept (Williams et.al. 2017) and is replaced by an intricate entanglement of inter- and intra-connections: an assemblage, in Goodley's (2017) words. That is, postconventionalist understandings lead us to a reconsideration of the human, where we 'consider the self as a decentred and distributed phenomenon deeply embedded in relationships with others' (Williams et al., 2017:45). We can see from this perspective the plethora of possibilities that disabled mothers make, engendering innovative designs and creative solutions. To engage with Crow's (2003:3) statement, the fact that disabled mothers are on the outside is not about us, it is about *their* failure. What postconventionalist ideas can bring, then, is 'an opportunity to think through values, ethics and politics that congregate around particular bodies' (Goodley & Runswick-Cole, 2012:5, cited in Williams et al., 2017:46). Perhaps a more productive question would be, 'How do disabled mothers offer more distributed, collectivist, innovative kinds of mothering that defy the normative script? Rather than symbolise disabled mothers as lacking, how are they potentially transformative?' These questions will not only have implications for the social and cultural position of disabled mothers, but may also have positive repercussions for all mothers, freeing them from the restrictive imperatives that constrain us all.

Disabled mothers need to find ways that they can mother on their own terms, to break free of the spell of compulsory able-bodied mothering. We need to learn from other misfits and create our own paths that resist and reform the cultural imaginary, and that question the necessity of autonomy at its centre. This sentiment is especially potent for me now as I nestle the beginnings of a second child deep within me, fortified by the blossoming potential of postconventional possibilities and the power of ableist critique.

CHAPTER ELEVEN: AGITATING ABLEISM

REFLECTIONS ON THIS PROGRAMME OF RESEARCH

11.1 Overview

This final chapter can be described as a discussion (as opposed to a conclusion). A conclusion signifies an end point, a satisfactory cessation that conveniently draws the entanglement of differing strands of the argument together to a point where the reader and I can stop, relax and say, ‘there’. There will be no such pause given here. I want to celebrate the inconvenience, the messiness and the hesitations that disabled embodiment contains. Following the spirit of postconventionalism, this thesis is intended to create more areas of concern than it answers. A Studies in Ableism (SiA, Campbell, 2009) perspective assists us in rooting out the concept of the ideal student, ideal mother and ideal researcher and ask ourselves, ‘do we really want to embody those characteristics? Why? Who does it benefit? Are there alternatives to this narrow and normative way of thinking?’ These are some of the questions I hope the reader will ask. As was maintained throughout this thesis, I do not claim to provide concrete, definitive answers to the research questions posed, but hope instead to stimulate conversations and dialogue surrounding these vital areas of concern. I aim to enliven the discourse that is overshadowed by the unquestioned acceptance of ableist ways of being, and to formulate possibilities for alternative ways of living life that reject neoliberal ableist strangulation.

Ableism has many cruel faces, and it presents itself in countless sly, stealthy, and underhand ways. This programme of research has attempted to address the potential psychological and emotional consequences of the presentation of ableism upon the psyche of disabled people. It has attempted to expose the practices of ableism, making the *dysconscious* conscious, recognisable and therefore contestable. This chapter will extract the most salient arguments from each of the three sites I explored in which ableism reared its loathsome head: ableism in speech and the research encounter; ableism in the lives of university students; and ableism in mothering ideology. It will then weave these indictments together to reveal a fine web of hegemonic conventions that both implicate and affect us all.

11.2 Disrupting speech

Accepted forms of speech mirror characteristics of the valued neoliberal citizen – efficient, fast-paced, to-the-point, unencumbered, smooth and articulate. Disabled speech juts and jostles against this, continually making demands upon the hearer who is highly conditioned to

the norms and pace of ‘normative’ verbal interaction. Speech performance is wedded to expectations of efficiency, clarity and pace. It is assumed that voices are autonomous, and that they deliver – unheeded - the values, thoughts and desires of a person. Autonomous speech is an assumption of the rational, competent citizen. You must be able to speak for yourself in order to have autonomy, independence and self-determination. What, then, of the communicational interplay of disabled voices? The valuing of speech has so far been given little attention in the field of critical disability studies, and that it is essential that it be given added consideration in ‘outing’ the ‘able’.

I noted that the commitment to ‘rationality’ and ‘objectivity’ in research signals a world in which the virtues of compassion and affinity are pushed down, accorded with little value and ultimately rejected. Every interview encounter is laden with context-dependent emotion, whether that emotion is overtly recognised or not. It is my view that the study of affect should be included as an indispensable faculty for the acquisition of human knowledge.

Following St. Pierre (2012), I re-cited speech as an act of reciprocal negotiation, calling for the listener to take some responsibility in the act of listening, re-citing verbal intercourse as an *interdependent* performance. This addressed the construction of normalcy in relation to speech. Broken speech, St. Pierre (2012) suggests, is more accurately attributable to the connection between the speaker and hearer. This sharing of the responsibility for broken speech is generally unheeded in day-to-day interactions, leaving dysfluent speakers open to a range of discriminatory and hostile responses.

I attempted to problematize the privileging of certain ways of being in the world that qualitative researchers have historically taken for granted, and question researcher’s role in supporting the ideology of a normative body and mind. Some qualitative research (Kerschbaum & Price, 2016, 2017; Rice et al., 2015; Linton, 1998; Chaudry, 2019) has moved in the direction of providing more equitable and non-normative ways of relating so that disabled people can participate in the research more effectively. Comparatively little research, however, has been conducted on the potential issues that disabled *researchers* themselves might encounter when faced with normative structures and expectations in the research encounter. Much of the guidance for qualitative researchers assumes an able-bodied interviewer. They are expected to be able to conduct the interview smoothly and effortlessly, and the conveyance (or not) of their voice is given little consideration. In producing this thesis, I have struggled to reorientate my speech dysfluency from an individual disorder that I

must atone for into a vital source of knowledge that informs my practice. This perceived ‘defect’ in my communication style has led to me becoming more aware of the potentialities of communicating differently, and led to me seeking to pursue a research design that tried to incorporate multiple ways of relating. The incorporation of ‘Crip time’ (McRuer, 2006) into methodological design may facilitate this. Crip time introduces the concept of flexibility, adaptability, insinuating time that is less rigid and obstinate to the needs of every body, and can be presented as a challenge to normative expectations of time and pace. Engaging in the act of disfluent research is to make a commitment to relationality; to focus more on our responsibilities as actively hearing components of the research process; and to critically evaluate the values and assumptions undergirding each way of relating. The concept of dis/fluency stimulates and exposes questions of why and how we value fluency. Dis/fluent speech draws in and complicates the hegemonic expectations of speech and hearing. The extent to which the valuing of speech passes by unnoticed –in other words, is a dysconscious act – is troubling, particularly in the research encounter. Through my engagement with the troubling nature of this valuation, I sought to open up a space for reflexively reconsidering normative assumptions in my research design.

11.3 Disrupting ableism in neoliberal education

The reason I chose to conduct this study is that educational institutions are one of the most important foundations of society, and thus a constructive site for the exploration of the psycho-emotional consequences of the dysconscious practices of ableism in society. Additionally, I was ideally placed to be a strategic insider-researcher, occupying a space that provided valuable insight into this process.

I will reorientate the reader with the three key research imperatives that I sought to address with Project One:

- How is the neoliberal ableist agenda inculcated into university institutions?
- How does this impact upon the psycho-emotional well-being of disabled students?
- What alternatives could be conceived of for the future of education that goes beyond the neoliberal agenda?

This project addressed the complex presentation of ableism in neoliberal education systems. Through my interpretation of the data gathered from this study, I teased out five interrelated recurring themes relating to this phenomenon: belonging; lack of appropriate support;

internalised ableism; when supports do work; and disability as productive. These were then used to expound upon the manifestation of ableism in university education and to think through the psycho-emotional consequences of these interactions for disabled students.

The theme of belonging is a pertinent one for many disabled people. The sense that one intrinsically belongs in a place is important for one's comfort and well-being. It was proposed, however, that practices of ableism conspired in numerous overt and covert ways to prevent my participants from feeling this sense of place-belongingness in their university settings. Feeling out-of-place with one's environment can create feelings of psychic disequilibrium, and this can have profound consequences for disabled students. The very architectural structure of university buildings can act as a flagrant deterrent for people with mobility issues, unashamedly stating 'you are not part of our design; you don't belong here'. This demonstrates the structural discrimination of disablist architectural design. But ableism as a concept seeks to implicate the genealogy of society in its perpetuation, and the unquestioned preference for those deemed able-bodied. This can be seen in the high expectations, from themselves and others, of disabled students at university. My participants for Project One reported that they felt extreme pressure to 'succeed' academically, and they were considered 'inspo porn' for others around them. Contrastingly, some participants reported feeling left behind due to stereotypical assumptions that they could not and would not succeed. These insinuations imply a deeper level of ableism, one that cannot be easily articulated or prevented but can do serious damage to the self-perception of disabled students. These insinuations are carried in the minds and actions of normative society, governing expectations of what a person can be or do. Acting in opposition to these expectations can require considerable emotional labour. These negative perceptions often become enfolded into the self-concept of disabled students themselves, arresting their development.

The lack of support and accommodations also affected my participants, reifying the lack of consideration given to ability privilege. This dysconsciousness around access issues needs vital recognition if ableist processes and practices are to be held to ransom. It requires significant emotional labour to negotiate the right support, as my participant's testimonies demonstrated. This can be seen as a barrier to success (as it is normatively valued) in the academic realm. The presence of disabled students in university education serves to uncover normative assumptions of the 'ideal' student through the labelling of what is *not* desirable, and the range of teaching practices that need to be accommodated for. Moreover, the language surrounding

accommodation smacks of normalisation, and does nothing to counter the assumption of ‘able as desirable’.

Disabled students are positioned in the ableist imaginary as unruly and demanding, in stark contrast to the vision of the ‘ideal’ student who is autonomous, self-regulatory, and compliant. This vision of themselves can be reabsorbed into the minds of disabled students, leading them to disavow and reject their disability, or endeavour to ‘pass’ as non-disabled. Both these reactions can cause a significant amount of psychological and emotional distress.

When my participants did feel that they had been sufficiently supported, it altered their experiences of university. The recurring theme that runs alongside these narratives is their treatment by individuals in their university settings. My participants reported feeling secure when teachers or other staff did not necessarily offer formal (and singular) assistance, but stated that they were available to help whenever they needed it. The insinuation was that their disabilities were not pointed out as problems in need of redress, but instead as part and parcel of the normal pressures of university life. This ‘no panic’ approach to disability signalled to my participants that they were accepted, and that their particular embodiment was only an issue if they felt it to be so.

Incorporating the reality of dependence into the core of our educational practice instead of vehemently pretending it doesn’t exist would begin to integrate notions of interdependence, of relationality, and of interconnection. My participants continually narrated an urge for educational institutions to move towards these attributes, signalling a move towards disability as *productive*.

Disability can be seen as a productive force – or a *Crip* force - in that it calls attention to and deflates the preferred neoliberal citizen of modern times. It also offers us a way out, a way of escaping the constrictive and oppressive rubrics of normative performance by offering other paths formulated as a response to living within Crip/queer modes of existence (Mitchell & Snyder, 2015). My participants offered alternative definitions of ‘ability’ that celebrate the notions of interconnection, of reciprocity, and interdependence. The critical study of ableism can be productive in the way that, through identifying the seepage of ableist values, we can recognise them and seek alternative ways of being.

11.4 Disrupting ableism in motherhood

This is another arena where the thorny brambles of ableism have snared the workings of society, infiltrating it with such moralistic values that it seems preposterous to question them. It is another area wherein I used my position of being an inside-researcher to my advantage, and made full use of the opportunity to interrogate yet another facet of ableism in practice.

We can see from Study Two that the requirement of being a ‘good neoliberal citizen’ and being a ‘good mother’ contradict each other, each fighting for prominence in the imperatives that a mother should follow. Arguably, this holds true for non-disabled and disabled mothers alike. The friction that disabled mothers face comes in the careful analysis of what it means to be a good mother. The devotion of all the waking hours to the care of the child is a prerequisite to be termed a ‘good’ mother; and that presents significant issues to mothers who have fluctuating energy levels or who need to devote attention to the care of themselves first and foremost. The infiltration of values that deny disabled motherhood are in danger of becoming an accepted ideology, and it is the dysconsciousness with which these processes are carried out that Study Two sought to expose.

I argued that ‘good’ parenting has been transformed into a set of skills which the discerning mother rushes to acquire. My research suggested that the valued characteristics of a ‘good’ mother are as follows: physical dexterity; fast pace; endless energy; emotional, mental and physical stability; and is self-reliant, independent and autonomous. ‘Mothers’, this ideology says, ‘have to make choices. These choices will determine their success or failure in producing the ideal neoliberal citizen –and thus one who has value in society’. The production of the idealised citizen is tied to market forces and the consumption of advice targeted at this population. I spoke candidly about my experiences as a first-time mother, and the trials of endeavouring to meet the standards that I felt were tacitly –but forcibly – set out for me. I acknowledge that the distress I felt was partly due to my own internal critic; but also acknowledge that this critique did not arrive in a vacuum. It was built upon layer upon layer of social expectations and obligations that I had readily absorbed from my social environment. It is not deemed to be culturally permissible to reject these values. Moreover, these views position the child as always vulnerable and always the same, denying the capacity of the child to adapt to different circumstances.

The medicalisation of pregnancy and motherhood that I explored in Chapter Eight is irrevocably tied to bio-politics and governmentality (Rose, 2001; Foucault, 2008) and the

production of the ideal neoliberal citizen. Rampant disablism is apparent with the promotion of prenatal testing, and dysconscious ableism rears its head with the acceptance that this is a necessary practice devoid of any concerns about the potential outcome of this custom. I identified the ableism in the provision of hospital facilities for disabled women. Previous research has pointed to the lack of accessible birthing rooms, for example, signalling that alternative embodiment is not considered, and therefore disallowed. Furthermore, my research reported instances of the comparative surveillance of disabled mothers, highlighting the mistrust and suspicion directed towards this population. The structural barriers to mothering with a disability too provide a more subtle message that disabled mothers are not considered in the sacred hallow of mothering ideology. This, as evidenced by my autoethnographical data, can cause significant damage to the psychological and emotional welfare of these mothers. Perhaps one of the most significant findings of this study is in the ways in which disabled mothers are enlisted in these efforts which so discriminate against them. Countless stories celebrate the ‘ability’ of disabled mothers to perform acts of mothering in normative ways. No consideration is given to the emotional labour involved in doing this, of trying to succeed *despite* their disabilities. Instead this research puts forward alternative ways of celebrating disability. This signals ways of performing motherhood *because of* the mother’s disability. The implicit acceptance that able-bodied ways of doing motherhood are the ideal is collaborating in the oppression of disabled motherhood. Offering methods of performing motherhood in normative ways – for example with the assistance of adaptive technology, risks obliterating and side-lining the particular knowledge that can be garnered from the experience of disabled mothering.

Mothering with a disability can be productive, and can have numerous beneficial effects on the children of disabled parents. A heightened sense of adaptability, for example, or an increased appreciation of different ways of being and moving in the world are prime examples. We need to increase the focus on these aspects instead of conforming to the narrow and harmful expectations that are neither sustainable nor realistic.

11.5 Ableism is indeed all around us; but let’s consciously interrupt its progress

At the beginning of this programme of research, I took as my claim that ableism is all around us. It is implicated in the practices and procedures of a range of institutions in society, and this thesis has attempted to unearth three instances of its occurrence. In doing this, we can see how these practices overlap and implicate each other.

The production of ableism can be seen through the hegemonic acceptance of child development theories which seek to impose categories of ‘normal’ and ‘abnormal’, and the values that should be attributed to them. This has the potential to infiltrate our expectations of one another.

The norms of pace and conventions governing speech interaction have an effect on the norms of research; which then have implications for who is to be counted. The paucity of research on disabled researchers signals that they are not expected within the conventions of research. The way in which disability is treated in universities – ‘you must conform to the norm, because there is no way we will conform to you’, is further evidence of ableism in practice.

The most troubling aspect of ableism as it manifests itself in practice, and the most relevant to this programme of research, is the effect that I propose it has on the psychological and emotional welfare of disabled people. When the infiltration of ableism is reinforced, empowered and justified by the forces of neoliberalism, as I inferred the case is with education, the consequences can be catastrophic. The messages that ableist neoliberalism sends – (‘You can do it if you really want’, ‘you have no-one to blame but yourself’, ‘you can do anything if you work hard enough for it!’), constructs the individual as an autonomous subject who only needs to ‘work hard’ and ‘take action’ to ensure a happy life. This, as I have insinuated throughout both studies, ignores a host of other factors contributing to the economic and social position of people in society. Carrying these messages in one’s head contributes to the internalised ableism that my studies showed have a significant effect on a disabled person’s self-esteem, sense of self-worth and confidence in one’s abilities.

This can lead to the frantic and exhausting compulsion of disabled people to emulate the norm, be that the ideal student; the ideal researcher; or the ideal mother. This is how we can all be implicit in perpetuating ableist practices. We need as a society to critically examine the values undergirding these idealisations so that we do not casually sustain the manifestation of ableist relations.

It can require extortionate amounts of emotional labour to push back against the unspoken rules and regulations of ableist normativity when all around you are trying to squash you into straining against all odds to become their version of the ideal student/mother/researcher; but I urge all of us to pause, take a step back, and analyse our actions, and thus make the dysconscious conscious, watchful and – most importantly - responsive.

The world is in crisis. At the time of writing it is 7th of May 2020, and every nation has been under varying degrees of lockdown (quarantine) since March of this year. This is because of the coronavirus, a deadly flu-like infection that is highly contagious. This global pandemic is frightening, particularly for those with underlying health conditions as the virus appears to target this population, although no-one, it seems, is immune from it. The insinuation, however, that we are all equally susceptible is perhaps erroneous. The lack of sign language interpreters on news bulletins, for example, or necessity of personal assistants to self-isolate may exacerbate the risks for disabled people.

The global death toll stands at 265,657 (worldometers.info/coronavirus); a conservative estimate as this only considers deaths in hospital wherein the cause of death was specified as coronavirus-related and thus ignores deaths that happened in homes or institutions. This state of affairs is undeniably horrific. These are profoundly unsettling times, and yet I tentatively and respectfully advance that perhaps they can be viewed as a time to rethink our lives; a time of productive possibility.

For example, disabled people have been fighting for years to have the right to work from home (Adams & Oldfield, 2012; Harpaz, 2002; Ludgate, 1997; Spark, 2017) and have often been refused this ‘accommodation’ on the grounds that it is not feasible or that it is too costly. Suddenly, now that non-disabled people need to work from home too, employers have been able to find ways around the obstacles that presented the grounds for the denial of granting this option to disabled people. Bittersweet as this may be for disabled people, at the very least it may help society to become more conscious of alternative ways of living life. Mitchell & Snyder’s (2015:22) urge – that we need to ‘reimagine ways of artfully living less productive, less consumptive and less exploitative lives’ has never been more relevant than it is today. These times demand a reconsideration of the values we –individually and collectively – hold dear. The rapid changes that have been made as an attempt to prevent the disease from spreading show that society is indeed capable of addressing some of the inequalities disabled people face. Let’s push for more.

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APPENDIX 1

THE RELATIVE MERITS OF QUANTITATIVE ANALYSIS

This report will think through the advantages and limitations of quantitative methods in exploring the position of disabled people in society. It will begin with an outline of the aims of my thesis, briefly covering the research questions that I am exploring and concisely reviewing the techniques used to inform my analysis. I will then elaborate on some of the possible uses of quantitative analysis in my two studies, and reflect on the advantages of this way of working. I will also introduce some of the possible questions that could have been asked to achieve quantitative data within the research area that I am pursuing.

Thesis aims

The overall aim of this thesis is to uncover instances of ableism – profound favouritism overtly and covertly displayed towards able-bodied citizens - providing contextual evidence of when it occurs and with what potential impact. In Study One, I used in-depth interpretive interviews to analyse data gained from 17 disabled individuals about their perspectives on the psycho-emotional consequences of ableism within academic institutions, and in Study Two I used a combination of autoethnographic data and literature review to analyse the impact of ableism within motherhood. Both these studies drew largely on interpretive data about the intricate and intimate lives of disabled people, and sought to weave a picture of how disabled people see themselves in relation to society. I sought to gather a multitude of voices to offer a

subjective understanding of this complex interaction and the impact of this relationship on disabled people's psyches. These types of question require a very personal, in-depth analysis of the meaning-making of people *in relation* to the particular environments they live in and how they see themselves as operating with/in their worlds. These experiential objectives had profound implications for my choice of paradigm, the methods I employed, and the techniques that I engaged with over the course of my work.

Study One proposed a number of questions with the aim of interrogating the extent to which ableism infiltrates university education worldwide. Conceivably, I could have asked a more operationally defined set of questions that may have provided me with definitive answers such as enquiring about participant's age, educational achievements, ethnicity, and other such background information. However I felt that these questions could have taken the focus away from the research areas that I wanted to address, which are around the psychological and emotional consequences of being taught in educational institutions that are engulfed by neoliberal, ableist values. Consequently, I narrowed my research questions down into the following four themes;

- How is the neoliberal ableist agenda inculcated into educational institutions?
- How does this impact upon the psycho-emotional well-being of disabled people?
- How do ableist expectations and individual subjectivities relate to one another, and how is this expressed?
- What alternatives could be conceived of for the future of education that goes beyond the neoliberal agenda?

Appendix 1 shows the basic questions that I asked in my qualitative interviews, but these were supplemented with other, ad hoc queries to fit with the natural flow of the conversational approach that I used. As these questions prompted very personal, unique responses I deemed it inappropriate to use quantitative analysis on the data received.

Quantitative analysis is an excellent means of presenting factual information, but the nuances and ambiguity of my data does not lend itself to statistical accuracy. The data I received is intricate and complex, and very difficult to interpret in the concise way that evidence gained from quantitative analysis would be. I feel that research on and with disabled people has to take nuances such as participants concerns and reluctance to answer personal questions into account. As my studies both focused on psychological and emotional data, I see qualitative methods as the only applicable means of interpreting the data I received.

I made great use of the qualitative method of autoethnography in my work as I feel that it can be an insightful way of relating personal troubles to wider social issues (Mills, 1959), and so Study Two detailed the momentous interruption (and subsequent integration) of pregnancy and motherhood into my life. Ableism in motherhood is rife, displayed particularly in the lack of products in the consumer market for disabled mothers; the practice of prenatal screening to detect for foetal anomalies; the lack of adequate provision for alternative embodiment in hospitals and leisure facilities; and the surveillance of this population driven by the assumption in the collective public genealogy that disabled women are incapable of performing mothering duties. This led to me pursuing a different set of questions to the ones originally intended, but this deepens my analysis of the position of disabled people in western society as it samples two important aspects of the inherent hegemonic preference of ablebodiedness. These questions were formulated as follows:

- What is it specifically that is valued in motherhood, and in what ways are these values ableist?
- How do we as a society uphold and reinforce these values?
- How can the study of ableism, in conjunction with a social psychoanalytical and post conventionalist approach, be used first to expose then to challenge and break down these stifling structures in order to forge a path for more creative mothering practices?

I sought to respond to these questions through a balance of autoethnographic data from my experience as a disabled mother and data gained from a thorough theoretical literature review. This was then analysed through a blend of critical social psychoanalytic, *Studies in Ableism* (Campbell, 2009) and postconventional perspectives. Again, I felt that quantitative analysis would be an inappropriate method of analysing this data as it is complex and cannot be easily attributed to numerical interpretation. So what would the potential benefits of quantitative analysis be? What questions could be asked that quantitative analysis could be applied to? The next section of this piece will provide possible applications of quantitative analysis in my work, and herald the numerous advantages of this way of working.

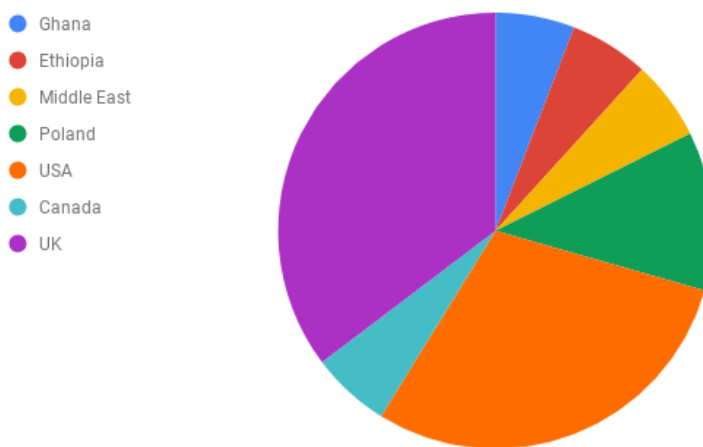
Potential applications of quantitative analysis in my work

I could have applied quantitative analysis to a number of questions - such as the standardised educational achievement of my participants; the languages spoken at home; how often they attended lectures or seminars; how many hours a week spent studying; how many units of

alcohol they consumed in a week; whether they had dependent children; whether or not they worked for pay alongside their studies; how much help they received from the state, financial or in other formats; whether the disabled mothers used assistive devices; their present housing situation etc. to see if these had any causal relationships to the stress and perceived discrimination levels they experienced. This may have provided a more rounded picture of my participants.

It may be useful to visually represent quantitative data that I did collect, for example country of origin of participants, as shown below:

Figure 2: Geographical reach of project



It would also have been particularly helpful in Study Two to have statistical evidence of the proportion of mothers who identified as having a disability, but this was not available from any of the organisations I contacted (the ONS (<https://www.ons.gov.uk/>), Scope (<https://www.scope.org.uk/>), Disability, Pregnancy and Parenthood (<https://www.disabledparent.org.uk/>), Mencap (<https://www.mencap.org.uk/>), Disability Rights (<https://www.disabilityrightsuk.org/>) and Best Beginnings (<https://www.bestbeginnings.org.uk/parents-with-disabilities>)). This information would have been useful to my analysis of disabled mothers as it would have shown the proportion of disabled women who do mother, and therefore the extent to which the ableism inherent within mothering ideology affects people's lives.

Outing neoliberal ableism using quantitative data analysis

If I'd have taken a more quantitative approach to my analysis, I could have asked questions such as:

- What percentage of disabled students a) apply to university, and b) succeed in gaining entry? This would answer the research question around the relatively low number of disabled students. An additional question could be asked around their attrition rates.
- What extra pressures do disabled students have? I could conduct a comparative analysis on the number of hours disabled students spent studying compared to their non-disabled counterparts. This may reveal added pressure on disabled students to achieve.
- How are ableist values inculcated into recruitment messages for the ten 'top performing' universities? I could perform quantitative content analysis (Krippendorff, 2004) on the number of times ableist words (such as self-reliant, self-sufficient, autonomous, independent, self-initiative etc.) were used in recruitment brochures, designing a specific process using unitising, sampling, coding, inferring and narrating (Krippendorff, 2004).
- How far do university selection processes reflect existing socio-economic inequalities? By formulating an in-depth survey of the entry requirements for a range of say 10 'top performing' universities, (i.e., selection from certain fee-paying schools, demographic statistics, race/religion selection etc.) I could see to what extent this supported existing socio-economic inequalities in the UK.

I could have asked similar fact-based questions to glean quantitative data for my Study Two:

- How restrictive are nurseries and schools for disabled mothers to access? I could conduct a survey around access issues, in conjunction with GPS data to give added validity to the responses received. This would give me concrete evidence for future recommendations. However this would require resources that are not available to me as a single researcher.
- How many children have been removed from their disabled mothers in the UK a) in the past 5 years and b) in the past 50 years? This would reveal the correlation between ableist values and mothering and the extent to which they are still present

How might quantitative analysis approach these topics?

Both of my studies analysed subjective, value-orientated psycho-emotional data, but the area I am researching, particularly for Study One, has been extensively pursued to achieve

quantitative data. One empirical study that made great use of quantitative statistical analysis to represent levels of self-efficacy and stress on the outcome of success in college students was undertaken by Zajacova, Lynch and Espenshade in 2005. Their study used a specially-developed survey instrument to assess the importance of being capable of, or at least believing oneself capable of, productivity and efficiency in academic situations, compared with levels of perceived stress in college-related tasks. They measured this in relation to three academic performance outcomes: the Grade Point Average attained, the number of accumulated credits, and whether or not the student's stayed in college (Zajacova et al., 2005). The advantage of this study, according to the authors, is that the aim is to examine the effect of academic self-efficacy and academic stress in relation to the *same* tasks, something that was missing in other similar studies. The authors expected to find a negative correlation between self-efficacy and perceived stress, meaning that the more the student feels themselves capable of achieving particular academic goals, the less stress they will perceive in relation to performing these tasks. They also expected grades, credits and persistence to have a positive correlation to each other. I have chosen to cite this study in particular as I am curious as to how the authors applied a quantitative lens to something like 'self-efficacy' that I would consider to be rather a complex term. I also wondered how they managed to quantify levels of stress, as these are emotive terms that I would find it difficult to calibrate.

This study was conducted amongst 107 participants, much larger than my study of 17. The measures of perceived stress related to academic tasks - such as writing papers or participating in class discussions - were measured on a Likert scale as to how stressful the participants found that particular task. These were then shown on the same table as the reported levels of self-efficacy. The authors chose to use an amalgamation of differing existing estimations of measuring self-efficacy and ones that were created to suit this particular study. In their limitations section, the authors did report the difficulty in assessing such an abstract concept as self-efficacy but used structural equation modelling to analyse the effects of stress and self-efficacy as latent constructs (variables that lack observable, measurable accuracy) on the outcomes. The LISREL approach was used to estimate the structural parameters of the factorial analysis by adopting the maximum likelihood method (Crisci, 2012). Both exploratory factor analysis (wherein the data is allowed to cluster into groups based on certain constraints on the model (Zajacova et al., 2005)) and confirmatory factor analysis (wherein data are tested against a model in order to confirm or dispute it) were used. For the structural equation modelling, the authors summed and averaged the items for

each factor, producing four indexes for self-efficacy and four for stress (Zajacova et al., 2005).

The results from these intricate mathematical models by and large confirmed the author's hypotheses. This may have been due to the kinds of questions they asked of the participants and the way in which these questions were asked, leaving no room for elaboration. The results confirmed that academic stress and self-efficacy exhibit a moderate to strong negative correlation. A chi-squared test was subsequently performed on both models used in the study, which revealed a statistically significant difference, meaning that although stress and efficacy are related, they exist independently. Whilst this thorough study has many benefits (namely, the generalisability and applicability of the study in other locations; the statistical analysis performed; the survey measurement techniques), it also has certain limitations that are important to mention. A concrete definition of self-efficacy is evaded somewhat, and this is rather peculiar given the relative importance attributed to it by the authors. The answers to the survey may be highly mood-dependent, and an array of factors may influence the responses. This is arguably true for any interview, although I would contend that it is somewhat mitigated by the use of asynchronous interviewing techniques like email. Another extremely limiting factor is that the participants themselves were not able to articulate what *they* saw as the main factors influencing their success or failure in the college environment. They may have been able to articulate different stressors that impacted on their success in college, but they were only able to decide which of the factors that had been priorly established by the authors of this study were the most significant in their academic lives. Finally, the measures of success were also limited to a conventional grading system, which may not adequately represent the potential of these students.

Another comparison of student achievement using quantitative analysis that is carried out worldwide is the PISA (Program for International Student Assessment, available from <http://www.oecd.org/pisa/>). This allows comparisons between the standardised achievements of students across the globe, and grants anyone with internet access to pit the supposed educational performance of one country against another. However, this scale only represents performance across three skills: science, maths, and reading. The test has been widely criticised for its lack in statistical transparency (Chalabi, 2013) and it was not possible to find a detailed description of the methodological procedure (other than the tests, demographic questionnaires, and the optional teacher and parent reports, of which there is extensive and detailed literature) on the original report. I had to search on a different page of the report

(<http://www.oecd.org/pisa/publicationsdocuments/statisticalsourcesandmethods/>) to establish how they actually analysed the findings, a report totalling 390 pages.

Quantitative studies on the subject of Study Two (ableism in motherhood) were more difficult to find, perhaps because of the hegemonic nature of this topic. Most studies on disabled parenting have been grounded in the medical model of disability which highlights parental incompetencies (see for example Buck & Hohmann, 1983; Green et al., 1995). There have subsequently been a number of *qualitative* studies carried out on exploring the experiences of disabled parents (see for example Booth & Booth, 2004 on the subject of children of disabled parents being taken into care) as I detailed in my study. Difficulty obtaining reliable information on the number of disabled mothers may be due to their reluctance to reveal disability for fear of surveillance. As mentioned, quantitative data analysis rests on vast amounts of data, typically conducted across wide populations. As I was unable to access exact data on the number of disabled mothers in the UK, I feel that this further strengthens my choice of qualitative analysis on this subject.

Other applications of quantitative data analysis in analysing the position of disabled people in our society

One aspect that quantitative analysis would be extremely useful to is analysing the employment statistics of disabled people relative to non-disabled people. This would provide an accurate picture of how disabled people are treated, respected, and accommodated in the world of work. For example, according to the Department for Work and Pensions statistics published in 2016, the 2012 Labour Force Survey stated that 46.3% of working age disabled people were in employment, but this was significantly less than non-disabled working-age people of whom 76.4 % were in employment (Labour Force Survey, Quarter 2, 2012). As quantitative statistical analyses are an extremely useful way of sifting through large amounts of empirical data this type of analysis would be much more useful to a large-scale project like accounting for the employment data of a whole country. A researcher could ask about the proportion of disabled people in different age groups currently in employment; whether there was a statistically relevant difference in the employment of disabled men in comparison to disabled women; what percentage of disabled people were currently in training (for example in university, college or vocational training). This would provide an accurate picture of disabled people's representation in a large sector of society.

Another really useful subject where quantitative analysis would be applicable relates to my Study 2. A researcher or research team could look at the number of accessible playgrounds or leisure facilities in the UK. To do this, they would need to develop a definition of ‘accessible’ (preferably in concurrence with a recognised organisation of disabled people) and apply it to the leisure facilities in a country or town, in this case the UK. A similar procedure could be applied to schools. This would provide indisputable evidence of the challenges that disabled parents face, and could be used in conjunction with qualitative methods to provide a nuanced representation of the *real* position of disabled people in society. For example, according to the government website (gov.uk), “Schools are *not* subject to the reasonable adjustment duty to make alterations to physical features, like adding ramps. They must make the buildings accessible for their disabled pupils as part of their overall planning duties” (<https://www.gov.uk/rights-disabled-person/education-rights>) (emphasis added). This means that the disabled person or parent does not have legal standing if a building is old or the school does not have resources to cover the alteration. Researchers have concentrated on this topic for school pupils (for example Bar et al., 1999; Orkwis & Mclane, 1998; Burgstahler, 2007), but these studies failed to take into account the position of disabled mothers accessing the school.

The benefits of Quantitative Analysis

If I conducted a quantitative study, I would be providing objective, indisputable facts about my participants that I could not gain through qualitative techniques. One of the major benefits of quantitative analysis is that it provides the researcher with concrete evidence in numerical form that is more difficult to dispute. A conscientious quantitative researcher, though, would still need to spend time outlining his or her positionality and reflect on the extent to which this has had an impact on things like the choice of method, the questions asked and the direction of the analysis. There is a danger inherent in ignoring or sidelining the impact of the researcher’s influence in both quantitative and qualitative methods, and this has the potential to skew the direction of the analysis performed.

Qualitative techniques have been criticised for their apparent lack of rigor and generalisability (Pattern, 1999). Critics can point to the lack of temporal sampling, the specificity of the sample, and the limitations of the selection of people sampled. This means that the data may not easily be generalised and applied in other settings. Thus, the use of

quantitative methods is arguably more respected in the field of social sciences as they provide relatively indisputable facts and figures that are akin to scientific work.

However, whilst quantitative methods are an excellent way of presenting observable, concrete facts about people's lives in the public arena such as their employment status or educational achievements, this threatens to overlook crucial aspects of their lives in the private sphere. Solely focusing on things like the increasing number of disabled employees, the differing range of accommodations offered, or the rise in the uptake of disabled students portends to mask the *actual* position *affectively* felt by many disabled people in our society. Laws may be in place to prevent discrimination happening, but this does not mean that disabled workers do not have to bear with snide remarks and hostility – derived in part from the insidious genealogy of ableism that haunts our society. This is particularly pertinent in the arena of disabled motherhood, where disabled mothers are still treated with animosity and suspicion, and in some cases automatically and vehemently denied their position as the mother (Campion, 1995). These observable victories in the public sphere threaten to distort the reality experienced by many disabled people in their personal lives. Therefore we need both quantitative analysis (to assess the wider status of disabled people in the community) and qualitative analysis (to provide distinct, subjective examples of life as it is viewed from the perspective of disabled people themselves).

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Appendix 1: Interview questions

- Can you tell me, in as much detail as you like, why you wanted to participate in this project?
- Tell me about your life in general. For example, how old are you, where do you live, what it is like there, do you have brothers/sisters/a close family....
- Thinking about your life in general, how do you feel other people have responded to your (disability)?
- How do you see yourself in relation to the society you live in?

Ok, now moving on to your thoughts on education.

- What do you think the goals or aims of education should be?
- What are/were the goals of education as expressed by your teachers/lecturers?
- What is 'ability' in your eyes? How would you define it?
- What does the term 'success' mean to you?
- In what ways do your definitions of these terms differ from those of your place of education?
- What are the pressures brought about by the focus on achieving 'academic success' for *individual* learners?
- Would you choose to define 'academic success' differently, and if so, how? What do you think would be the results of this?
- How do you think academic achievement should be measured, if at all?
- Do you think there should be some 'key' subjects to master? Why? What could be the consequences of this?
- In what ways have your experiences of education shaped you?
- Do you think that your teachers' reaction to your disability helped or hindered you? In what way?
- Can you tell me specifically anything that your teachers/lecturers did that helped you?
- Can you tell me specifically anything that your teachers/lecturers did that you felt hindered you?
- Do you feel that education should be delivered to meet specific needs, and if so, how?
- How did your educational experiences make you feel?
- If you could make changes to your educational experiences, what changes would you make?
- If you didn't have a disability, do you think your experiences of education would have been different? In what way?

- If you could make any changes to the education system in general, what would they be?
- How do you think that this would benefit you?
- Would you like to share anything else in your story?

REPORT CAPTURING DISABLED PEOPLE'S POSITION IN SOCIETY

Introduction

This appendix will demonstrate an application of quantitative analysis to assess the position of disabled people's representation in work and employment in the UK in contemporary society. I will briefly make use of several differing reports that use statistical data to suggest contradictory evidence as to how disabled people are regarded in the world of work, but this part of the thesis will focus primarily on the published data on the labour market status of disabled people in the Office for National Statistics (ONS). This comprises of data gathered from the Labour Force Survey (LFS) from the period 2015-2018 to record the number of disabled people in employment. The reason I have chosen to report this data specifically is that it purports to give coverage of disabled people's employment status over time. In 2013 there were important changes to the questionnaire used in the LFS, resulting in significant changes to the self-reporting of individuals as disabled or not disabled. These changes were made by the 2013 "Harmonised Standard Definition of Disability" (Hankins & Chandler, ONS 2016). This new definition caused a drop in April-June 2013 in the overall reporting of disability by 0.9% (390,000 people) and this was most reflected in the economically active population of disabled people (0.5%, 204,000 people) (Hankins & Chandler ONS 2016:1). This was done with the aim of bringing the definition of disability into line with the Government Statistical Survey (GSS) harmonised standards for questions around disability issues and the 2010 Equality Act, which replaced the Disability Discrimination Act (DDA) OF 1995.

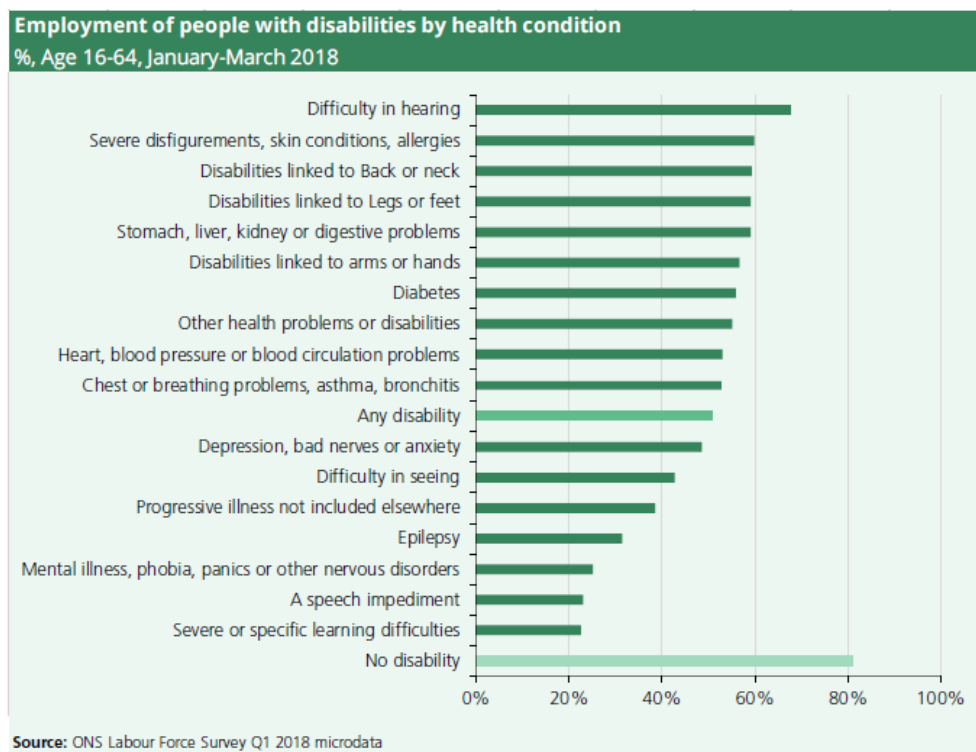
The main change in the 2013 wording was a shift from using the terms 'disabilities or long term health problems' to 'physical or mental health conditions or illnesses'. The new questions do not refer to disabilities at all and make specific mention of mental health conditions which was not done previously. Also guidance notes required respondents to consider their health problem without medication. Now respondents are asked to consider their health problem with medication.

(Hankins & Chandler, ONS, 2016:2).

According to this report, the people who changed their response to 'not disabled' after the harmonisation were more likely to suffer from heart, blood pressure or circulation problems; chest or breathing problems; or diabetes (Hankins & Chandler, ONS 2016:2). This removed a significant proportion of economically active disabled people from the category 'disabled'.

This suggests that under the new more stringent definition of disability, less people reported disabilities. It focuses on the present restrictions of activity, which removes people with progressive conditions, HIV, cancer and multiple sclerosis. Appendix A refers to the new questions asked under the Harmonised Standard Definition.

Details of the LFS report on the labour market status of disabled people will be given below, but in general it gives a fairly optimistic picture of the trend of disabled people’s employment prospects with 50.7% of people in employment (LFS 2018). However, these overall statistics conceal the realities experienced by many disabled people according to the data published from the Trade Union Congress (TUC) in 2011, where little more than 10% of people experiencing mental health issues were employed, and only 15% of those identified with learning difficulties (TUC report 2011:4). This trend continues to the present day, with “less than a quarter of people with learning difficulties, a speech impediment or mental health conditions” (Powell, HoC, 2018:9) in employment as is shown by the following graph:

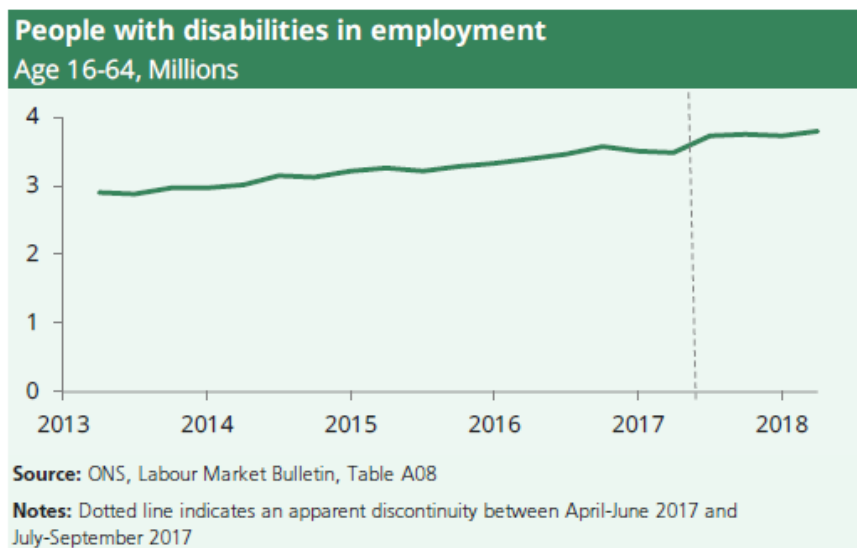


(Powell, HoC 2018:4)

Additionally, according to the data gathered from the disability charity Scope one in five employers state that they would be less likely to employ a disabled person (Scope, 2017).

Using a different definition of disability, one taken from the Equality Act of 2010, the TUC declare that even when they do succeed in finding employment disabled employees earn “substantially less” than their non-disabled counterparts, 15% less based on the Quarter 3 2016 and Quarter 2 2017 earning figures (TUC, 2018:5), and disabled people are more than twice as likely to be unemployed than non-disabled people (LFS, April-June 2017).

However, according to the Department for Work and Pensions (DWP) 9 in 10 disabled people who are not in work are economically inactive and are not actively looking for work (DWP, October 2016). As we will see, the number of disabled people in employment from April- June 2013 to April – June 2018 has risen by around 900,000, an increase of 31% (Powell, HoC 2018:5) as the graph below shows. This is compared with an increase of 5% for non-disabled people in the same period.



The period that I am covering in this report is from April 2015 to June 2018¹.

¹ It is important to mention that the data contains a discrepancy, stated by the researchers, between April-June 2017 and July-September 2017. Investigations into the causes of this discrepancy are inconclusive, and therefore these figures are to be treated with caution.

Table 1: Economic activity of people with disabilities aged 16-64: levels, UK

Date of publ 14th August 2018

United Kingdom (thousands) not seasonally adjusted

	Harmonised Standard Definition Disabled ¹					Not Harmonised Standard Definition Disabled (excluding those who did not state their health situation) ²					Total aged 16-64: Including those who did not state their health situation
	Total	In Employment	Unemployed	Economically active	Economically inactive	Total	In Employment	Unemployed	Economically active	Economically inactive	
Apr-Jun 2015	7,096	3,257	425	3,682	3,414	33,503	26,526	1,362	27,888	5,615	40,839
Jul-Sep 2015	7,071	3,225	422	3,647	3,424	33,534	26,878	1,384	28,262	5,271	40,882
Oct-Dec 2015	7,029	3,277	384	3,661	3,367	33,600	26,970	1,229	28,199	5,401	40,923
Jan-Mar 2016	7,114	3,334	395	3,729	3,385	33,550	26,818	1,248	28,066	5,485	40,963
Apr-Jun 2016	7,077	3,388	377	3,766	3,311	33,597	26,898	1,205	28,103	5,494	41,003
Jul-Sep 2016	7,184	3,467	386	3,852	3,332	33,584	27,033	1,277	28,310	5,274	41,038
Oct-Dec 2016	7,204	3,568	364	3,932	3,272	33,592	26,983	1,156	28,138	5,454	41,071
Jan-Mar 2017	7,160	3,507	353	3,860	3,300	33,697	27,037	1,150	28,187	5,510	41,103
Apr-Jun 2017	7,097	3,492	346	3,838	3,258	33,792	27,223	1,085	28,308	5,484	41,136
Jul-Sep 2017	7,488	3,728	390	4,119	3,369	33,429	27,105	1,072	28,177	5,252	41,162
Oct-Dec 2017	7,425	3,755	378	4,132	3,293	33,487	27,166	1,016	28,181	5,306	41,185
Jan-Mar 2018	7,361	3,734	376	4,109	3,252	33,562	27,207	1,008	28,215	5,347	41,208
Apr-Jun 2018	7,491	3,798	368	4,166	3,325	33,451	27,136	941	28,076	5,374	41,232

SPECIAL NOTE : As a result of an apparent discontinuity in the LFS data comparisons should be made with caution between April to June 2017 and subsequent time periods. It should also be noted that the estimates are not seasonally adjusted so some of the change between quarters could be due to seasonality.

¹ Government Statistical Service harmonised standard definition of disability.

² Includes people reporting a health problem but are not classified as having a long-term health problem or disability under the Government Statistical Service harmonised standard definition of disability. Respondents who did not answer questions on their health situation are not included in the estimates presented here.

Table 2: Economic activity of people with disabilities aged 16-64: rates , UK

Date of public 14th August 2018

United Kingdom, rate (%), not seasonally adjusted

	Harmonised Standard Definition Disabled ¹				Not Harmonised Standard Definition Disabled (excluding those who did not state their health situation) ³			
	In Employment	Unemployed ²	Economically active	Economically inactive	In Employment	Unemployed ²	Economically active	Economically inactive
Apr-Jun 2015	45.9	11.5	51.9	48.1	79.2	4.9	83.2	16.8
Jul-Sep 2015	45.6	11.6	51.6	48.4	80.2	4.9	84.3	15.7
Oct-Dec 2015	46.6	10.5	52.1	47.9	80.3	4.4	83.9	16.1
Jan-Mar 2016	46.9	10.6	52.4	47.6	79.9	4.4	83.7	16.3
Apr-Jun 2016	47.9	10.0	53.2	46.8	80.1	4.3	83.6	16.4
Jul-Sep 2016	48.3	10.0	53.6	46.4	80.5	4.5	84.3	15.7
Oct-Dec 2016	49.5	9.3	54.6	45.4	80.3	4.1	83.8	16.2
Jan-Mar 2017	49.0	9.1	53.9	46.1	80.2	4.1	83.6	16.4
Apr-Jun 2017	49.2	9.0	54.1	45.9	80.6	3.8	83.8	16.2
Jul-Sep 2017	49.8	9.5	55.0	45.0	81.1	3.8	84.3	15.7
Oct-Dec 2017	50.6	9.1	55.7	44.3	81.1	3.6	84.2	15.8
Jan-Mar 2018	50.7	9.1	55.8	44.2	81.1	3.6	84.1	15.9
Apr-Jun 2018	50.7	8.8	55.6	44.4	81.1	3.4	83.9	16.1

SPECIAL NOTE : As a result of an apparent discontinuity in the LFS data comparisons should be made with caution between April to June 2017 and subsequent time periods. It should also be noted that the estimates are not seasonally adjusted so some of the change between quarters could be due to seasonality.

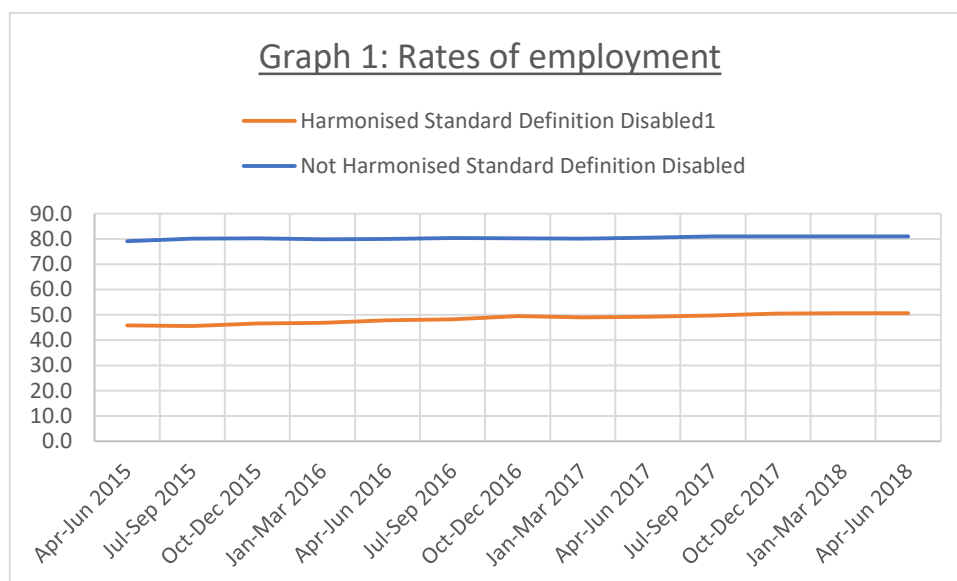
¹ Government Statistical Service harmonised standard definition of disability.

² Includes people reporting a health problem but are not classified as having a long-term health problem or disability under the Government Statistical Service harmonised standard definition of disability. Respondents who did not answer questions on their health situation are not included in the estimates presented here.

(Source: ONS Labour Force Survey 2018)

We can see from these tables that the employment rate of people who were *not* Standard Definition Disabled in April- June 2018 is 27,136 out of a total of 33,451 (reflecting an 81.1% employment rate). The employment rate of those who *were* Standard Definition Disabled for the same period was 3,798 out of a total of 7,491 which reflects an employment rate of 50.7%. From these figures, we can see that *not* being Standard Definition disabled

significantly increases the chances of being in employment and this can be seen in the graph below.



Adapted from Labour Force Survey, 2018: Table A08

This is also the case when broken down by gender:

Table 3: Economic activity of males and females aged 16-64: levels, UK.

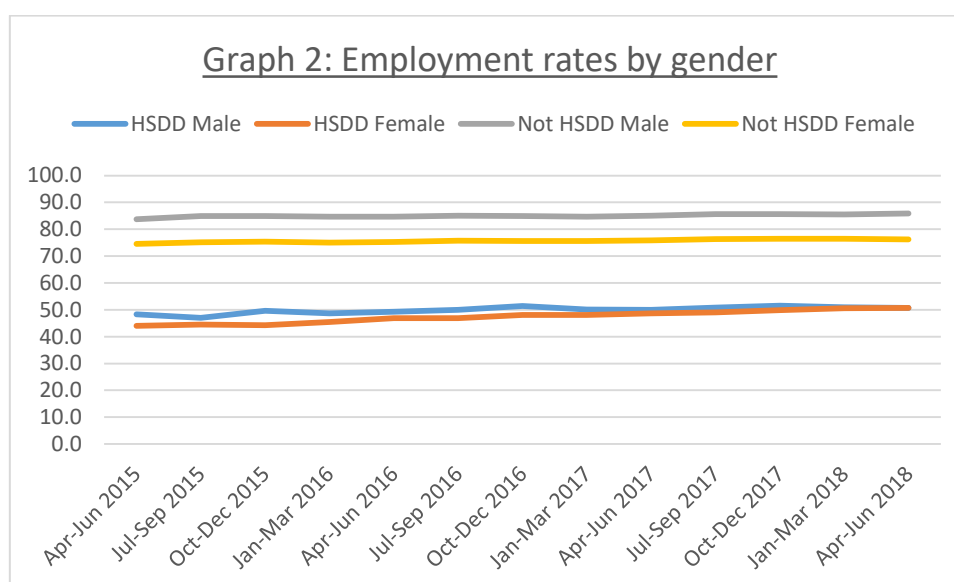
	United Kingdom (thousands) not seasonally adjusted												Total aged 16-64: Including those who did not state their health situation
	Harmonised Standard Definition Disabled ¹						Not Harmonised Standard Definition Disabled (excluding those who did not state their health situation) ²						
	Total	In Employment	Total Male	No. of males In Employment	Total Female	No. of females In Employment	Total	In Employment	Total Male	No. of males In Employment	Total Female	No. of females In Employment	
Apr-Jun 2015	7,096	3,257	3,164	1,527	3,932	1,730	33,503	26,526	16,993	14,218	16,510	12,309	40,839
Jul-Sep 2015	7,071	3,225	3,090	1,453	3,981	1,772	33,534	26,878	17,073	14,502	16,461	12,376	40,882
Oct-Dec 2015	7,029	3,277	3,096	1,535	3,933	1,742	33,600	26,970	17,085	14,518	16,515	12,452	40,923
Jan-Mar 2016	7,114	3,334	3,122	1,520	3,992	1,814	33,550	26,818	17,079	14,461	16,471	12,357	40,963
Apr-Jun 2016	7,077	3,388	3,055	1,505	4,022	1,884	33,597	26,898	17,156	14,523	16,441	12,375	41,003
Jul-Sep 2016	7,184	3,467	3,099	1,551	4,085	1,916	33,584	27,033	17,160	14,599	16,424	12,434	41,038
Oct-Dec 2016	7,204	3,568	3,171	1,631	4,033	1,937	33,592	26,983	17,097	14,513	16,496	12,470	41,071
Jan-Mar 2017	7,160	3,507	3,108	1,557	4,052	1,949	33,697	27,037	17,203	14,559	16,494	12,479	41,103
Apr-Jun 2017	7,097	3,492	3,075	1,536	4,022	1,956	33,792	27,223	17,250	14,673	16,542	12,550	41,136
Jul-Sep 2017	7,488	3,728	3,353	1,703	4,135	2,025	33,429	27,105	16,992	14,554	16,437	12,551	41,162
Oct-Dec 2017	7,425	3,755	3,321	1,710	4,104	2,045	33,487	27,166	17,034	14,593	16,453	12,573	41,185
Jan-Mar 2018	7,361	3,734	3,265	1,662	4,096	2,072	33,562	27,207	17,097	14,614	16,465	12,592	41,208
Apr-Jun 2018	7,491	3,798	3,321	1,684	4,170	2,114	33,451	27,136	17,039	14,623	16,411	12,513	41,232

Adapted from Labour Force Survey 2018: Table A08

Table 4: Employment rates of males and females aged 16-64: levels, UK.

	Harmonised Standard Definition Disabled		Not Harmonised Standard Definition Disabled (excluding those who did not state their health situation)	
	Male	Female	Male	Female
Apr-Jun 2015	48.3	44.0	83.7	74.6
Jul-Sep 2015	47.0	44.5	84.9	75.2
Oct-Dec 2015	49.6	44.3	85.0	75.4
Jan-Mar 2016	48.7	45.4	84.7	75.0
Apr-Jun 2016	49.3	46.8	84.7	75.3
Jul-Sep 2016	50.0	46.9	85.1	75.7
Oct-Dec 2016	51.4	48.0	84.9	75.6
Jan-Mar 2017	50.1	48.1	84.6	75.7
Apr-Jun 2017	50.0	48.6	85.1	75.9
Jul-Sep 2017	50.8	49.0	85.6	76.4
Oct-Dec 2017	51.5	49.8	85.7	76.4
Jan-Mar 2018	50.9	50.6	85.5	76.5
Apr-Jun 2018	50.7	50.7	85.8	76.2

Adapted from Labour Force Survey 2018: Table A08



Adapted from Labour Force Survey 2018: Table A08

Methodology of the A08 and LFS

The Labour Force Survey is the largest regular social survey in the UK, with 38,000 responding (or imputed) households. This represents approximately 0.15% of the population of Great Britain and 0.21% of the population of Northern Ireland (LFS Volume 1, 2016:9). The survey covers private households, NHS accommodation and halls of residence. The LFS operates on a rotational design, wherein one household takes the interview for five consecutive quarters with interviews being scheduled 13 weeks apart. The Primary Sampling

Unit (PSU) is the address, not the people living there which means there is a potential for drastically different results from one PSU.

Sampling frames and sample selection

For the purposes of this survey, Great Britain is divided into two regions – south of the Caledonian Canal and north of it, with the south comprising most of Scotland, and all of England and Wales. The south is sampled through the Postcode Address File, a computerised file that is updated every 6 months by the ONS. Wave One identifies 16,640 addresses which are ordered geographically, then draws a selection systematically with a fixed interval. This interval, k , is calculated by dividing the total number of addresses by 16,640. This gives a 1 in 1586 Wave 1 quarterly sample size. All addresses are allocated to pre-determined interviewer areas and to weekly stints, 13 of which make up the quarter's interviews. The sampling procedure for north of the Caledonian Canal is different as this area is sparsely populated, and so is done by telephone interviewing. This is of course imperfect as it is limited to those who are registered with the telephone directory and precludes those who have a mobile phone only. The system for Northern Ireland is similar to PAF, using the POINTER government register for domestic properties.

Interviewer area allocations

The selected sample falls within 208 interviewer areas, and these are then split into quotas, two in each interviewed area. Each quota is divided into 13 stints which are allocated randomly to the 13 weeks of the quarter. The systematic random sample of addresses is matched to its quota on postcode to provide a list of addresses to be interviewed each week (LFS Volume 1, 2016:17). A 'leap week' is introduced periodically to realign LFS quarters with the calendar year.

Data Collection Modes

There are 16,640 addresses sampled in Great Britain; plus 80 north of the Caledonian Canal; 650 in Northern Ireland and 9 units of NHS accommodation. This gives a total of 17,380 addresses. There are 5 waves in any quarter, which means 86,900 interviews. Most households south of the Caledonian Canal in GB are interviewed face-to-face in Wave 1, and then if possible by telephone afterwards.

There is a letter sent to every address in the sample, stating the purpose of the LFS and the importance of participating. 208 interview areas, containing an equal number of delivery

points, are selected. This is sub-divided into 412 quotas, and then divided further into 13 ‘stint’ areas by grouping postcode sectors. In December 2016, there were approximately 672 interviewers and 190 telephone interviewers (LFS Volume 1 2016:28).

The Questionnaire

The questionnaire contains a set of core questions that will not change over time, such as ethnicity, sex, and nationality and will only be asked at Wave 1 interview. Some core questions have to be asked at every interview without reference to previous answers and the responses coded, for example WRKING would relate to whether the respondent had a paid job in this Wave period; ED4WK would relate to whether the respondent had had job related education or training in the last four weeks etc. There is rigorous testing of the interview questions before the questionnaire is distributed to see if the questions are “acceptable and understood” (LFS Volume 1, 2016:26) by the respondents. In some cases, a ‘don’t know’ response will be accepted, but normally this renders the whole record unusable, for example questions related to sex, marital status, whether the respondent had been doing work for their own or a family member’s business, or whether they had had days off work due to sickness or injury. Proxy interviews are also accepted in cases wherein a person struggles with English or they operate as a carer for a member of the household, but this increases the likelihood of discrepancies in the accuracy of information.

Computer Assisted Interviewing (CAI)

Face-to-face and telephone interviewers both use the same software package to analyse the data, produced using the BLAISE CAI. This takes the output from BLAISE and uses it to create derived variables to weight up population estimates. This is used in conjunction with editing by the interviewer to ensure the data given is correct, and thus ensures greater accuracy and speed over a pen-and-paper approach.

Most of the coding of the interview is carried out by Computer Assisted Coding (CAC) during the interview, but other more complex codes are carried out afterwards by the interviewer. Stringent data checks to maintain the quality of the data are carried out once the data has been received from the field or telephone units. Coding is used to transform open-ended responses into categories. The codes are either automatically chosen by the computer or the computer suggests a list of possible codes to the human coder.

Non-sampling errors

Sampling errors occur when data from a sample is used to make inferences about the whole population. Non-sampling errors affect the data from sample surveys, and they are often incurred by conscious decisions taken by the research team to ensure low cost of data. The total survey error is measured by the mean squared error, which is defined as the sum of all biases and variances (LFS Volume 1, 2016:45)

$$\text{MSE} = \text{variance} + \text{bias}^2$$

Accuracy defines the quality of a survey estimate, and reflects the difference between the survey estimate and the population parameter being estimated (LFS Volume 1, 2016:45). The error in an estimate is described by the bias and the variance in that estimate, the two components of the total survey error, where low accuracy means high survey error. The bias could be as a result of errors of non-observation, wherein the sample is not representative of the whole population, and fails to take into account the views of non-respondents who may be radically different from the sampled population; and errors of observation, wherein there may be an unwillingness of respondents to admit to undesirable behaviour. The sampling variance also needs to be taken into account, wherein the results may have been different if an alternative sample had been selected; and the non-sampling variance wherein differences are observed between interviewers eliciting diverse responses to interview questions. The larger the sample size, the higher the precision. In LFS, the threshold for reliability is a sample size of 10,000 (LFS Volume 1, 2016:57).

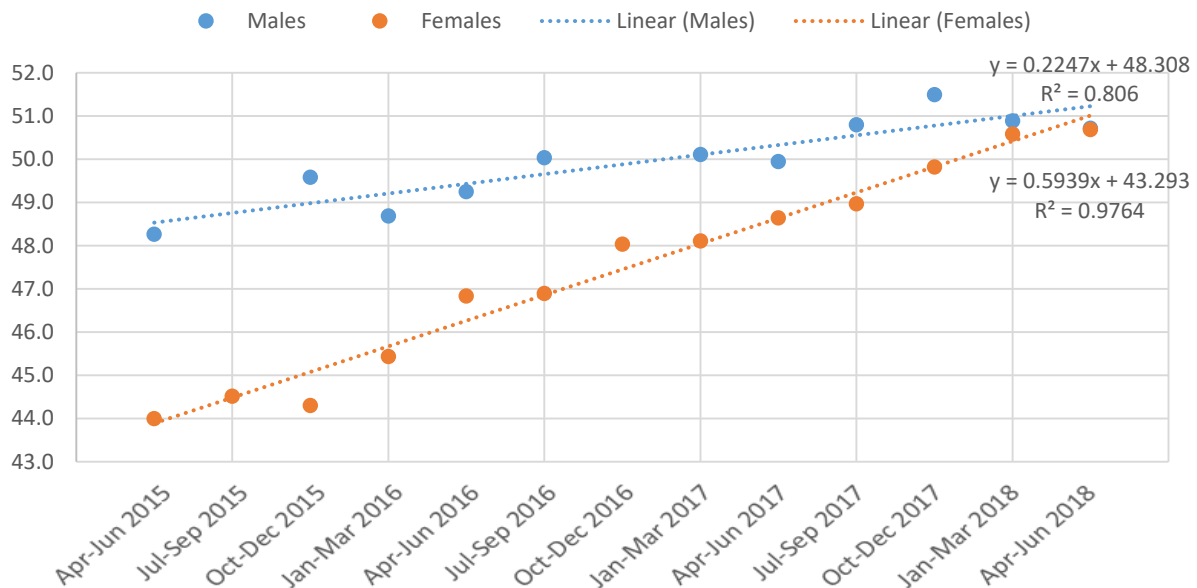
My analysis of the data

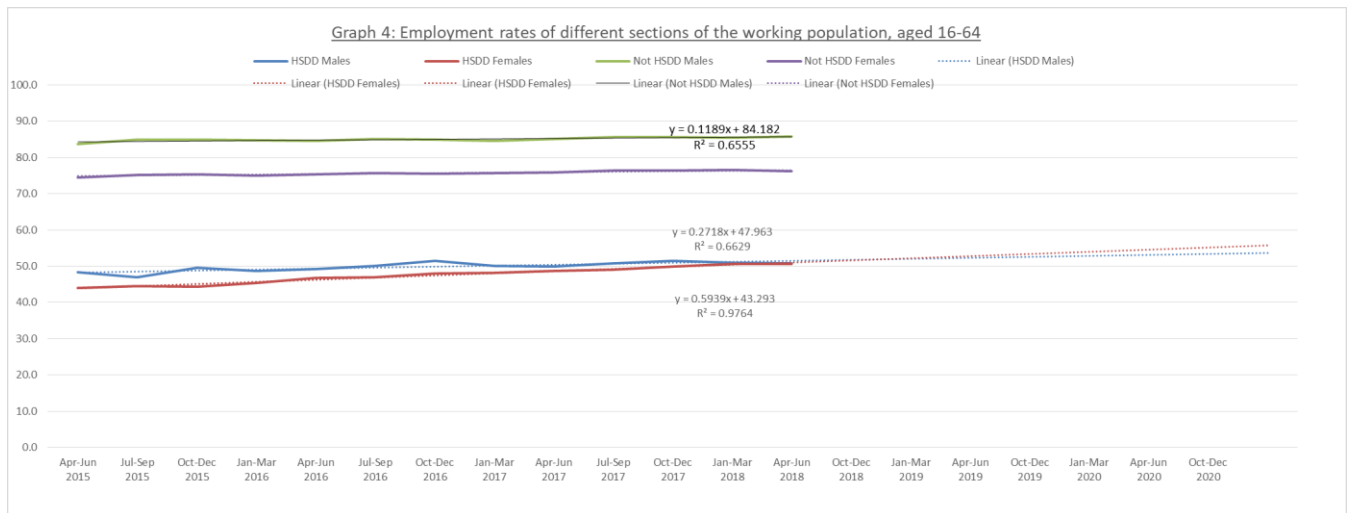
My research question for this data set was, ‘does gender affect the employment status of disabled people?’ I expected the employment trend to follow that of non-disabled people and for there to be a significantly higher proportion of men in comparison to women in employment. To do this, I began by selecting from the available data the employment information of HSDD (Harmonised Standard Definition Disabled) males and females. ‘*r*’ is the correlation coefficient which measures the strength and direction of a linear relationship between two variables. *r* is always stated as between -1 and 1, indicating a strong negative correlation and strong positive correlation at these extremes. Spreadsheet functions of the software package Excel were used to calculate the *r* values between the sets of data, for example between HSDD males and females, from April 2015 to June 2018. The statistical function CORREL was selected, and the two columns highlighted. This returns the correlation coefficient between the two data sets, which was then changed to three decimal

places. r in this case was 0.817, indicating a strong positive correlation – as the rate of employment of disabled males increases, so does the rate of females. This shows that there is a clear, strong linear trend between the variables.

However, when plotted on a graph, although the data points are clustered closely to the trend line, the r^2 value of the lines is less than 1, at 0.66 and 0.65 for HSDD males and females respectively. The r^2 value shows how close the results are to a linear trend, with trend lines closest to 1 allowing the most accurate predictions. However, as these are demographic figures with many variables, they are not precisely repeatable so some discrepancies are to be expected. For example, the period of July- September 2015 does not fit this trend. This is also true for the period October- December 2016. But, by removing these two data sets we can produce a line with r^2 much closer to 1, 0.81 and 0.98 for HSDD males and females, to show an overall trend, and thus make a prediction. The prediction is that by the end of 2018, the number of disabled women in employment will equal the number of disabled men in employment and females will overtake males in 2019.

Graph 3: Comparison of employment of disabled males and disabled females





Conclusion

The figures from the A08 Labour Status of Disabled People, obtained from the Office for National Statistics, appear to represent a positive outlook for the future employment of disabled people. However statistics tell us very little about the personal circumstances of these people and the cost to a) their emotional well-being and b) their health when a person who would previously site themselves as disabled is deemed fit to work. The overall employment statistics gathered by the LFS also tell us very little about what kinds of job the disabled people in employment have, or how much they are paid in relation to non-disabled people.

In the 2017 Conservative Manifesto, the government pledged to get 1 million more disabled people into work (Powell, HoC 2018:12), stating that this would save the exchequer £240 million (Powell, HoC 2018:12). On the surface this appears to be a positive promise, but the psycho-emotional consequences of this move upon disabled people themselves must be taken into account. Additionally, there needs to be a societal shift in order for employers to recognise the potential benefit and values of employing a disabled person. The government have a scheme in place to encourage employers to employ disabled people called the Disability Confident scheme (more details of which can be found on the gov.uk website). This involves employers signing up to, and providing evidence of, their delivery on various commitments to ensure that the recruitment messages for vacancies are delivered in an accessible format; that disabled people are given interviews if they meet the required specifications of the job; that they are provided with reasonable adjustments in order to perform said job; and that existing disabled employees are supported in maintaining their job roles (Powell, HoC 2018:12). Currently, this scheme is voluntary, but in order for the

Conservative government to reach the pledge set out in their manifesto, I suggest that Stage I of the Disability Confident scheme be made mandatory. This would help pave the way to a fairer society.

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Appendix 1

LFS QUESTIONS (before April 2013)	HARMONISED QUESTIONS (April 2013 and onwards)
<p>LINGLIM</p> <p>Do you have any <u>health problems or disabilities</u> that you expect will last for more than a year?</p> <p>1 Yes</p> <p>2 No</p>	<p>LINGLST</p> <p>Do you have any <u>physical or mental health conditions or illnesses</u> lasting or expected to last 12 months or more?</p> <p>1 Yes</p> <p>2 No</p> <p>Spontaneous only:</p> <p>3 Don't know</p> <p>4 Refusal</p>
<p>HEALIM</p> <p>Do these health problems or disabilities, when taken singly or together, substantially limit your ability to carry out normal day to day activities? <u>If you are receiving medication or treatment, please consider what the situation would be without the medication or treatment?</u></p> <p>1 Yes</p> <p>2 No</p> <p>3 Don't know</p>	<p>LIMACT</p> <p>Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities?</p> <p>Running prompt:</p> <p>1 Yes, a lot</p> <p>2 Yes, a little</p> <p>3 Not at all</p> <p>Spontaneous only:</p> <p>3 Don't know</p> <p>4 Refusal</p>

INFORMATION SHEET FOR PROJECT ONE

Interrogating Ableism: Exploring the Psycho-emotional Consequences of Neoliberal Able Education.

You are being invited to take part in a research project with the above title. Before you decide whether or not you wish to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and feel free to ask me any questions if there is anything you are unsure about. Thank you for reading this!

What is the purpose of the project?

This project aims to explore disabled people's experiences of a market-driven, normalising education system which is focused on a narrow concept of academic success. Being a valued citizen is based on limited and precarious standards, and judgement based on rigid and exclusive evaluations of ability has become so entrenched in society that it has become accepted as the way society *should* operate. This can be defined as *ableism*. People whose minds and bodies do not conform to these standards are marked out as 'other', as 'deviant'. This project will investigate the psychological impact of being defined as 'other', and will begin to formulate new ways of teaching and learning that are more inclusive and more responsive to the needs of disabled students.

The study will have a strong relational, feminist basis and will last around one academic year (8-10 months).

Why have I been chosen?

You have been chosen because you have a unique perspective on this particular topic, and I feel you will have many valuable insights to share and contribute to the research community. Around twenty other people have been selected to take part.

Do I have to take part?

No, participation in the project is entirely voluntary and you can withdraw from the process at any time. If you do decide to take part you will be given this information sheet to keep and invited to choose your preferred way of relating your story to me. You will then be asked to sign a consent form. You can withdraw from the study at any time, even after signing the consent form. If you choose to withdraw, any information pertaining to you will be destroyed.

What will I have to do?

How you present your stories to me will be up to you. You can choose email (via an account set up specifically for the purposes of this research: jdparticipant@mail.com), Skype, diaries, poetry, drawing, photography, video or even sculpture. I don't mind, as long as you are comfortable in this format. The e-mail and Skype interviews will be semi-structured, allowing for differences in experience to be respected and validated, but will be centred on addressing the following:

- What do you think are the goals or aims of education?

- What is ‘ability’ in your eyes?
- What does the term ‘success’ mean to you?
- In what ways do your definitions of these terms differ from those of your place of education?
- What are the pressures brought about by the focus on achieving ‘academic success’ for individual learners?
- Would you choose to define ‘academic success’ differently, and if so, how? What do you think would be the results of this?
- How do you think academic achievement should be measured, if at all?
- Do you think there should be some ‘key’ subjects to master? Why? What could be the consequences of this?
- In what ways have your experiences of education shaped you?
- How did your educational experiences make you feel?
- If you could make changes to your educational experiences, what changes would you make?

If you choose reflexive diaries as your preferred method, you will be asked to record your experiences on Word in a diary format, and then encouraged to submit these responses via e-mail. You can record these daily, monthly, or on an ad hoc basis, and the choice of whether to submit these entries will be yours alone. Similarly, if you choose poetry or song writing, you will be asked to send me a copy via Word and/or as an audio file.

This data will then be combined with my autoethnographical data on my own experiences as a disabled person within a neoliberal education system. The hope is that together we can work to promote alternative practices with the notion of *enabling* students at its core.

Will everything be kept confidential?

Yes, everything will be stored on a password-protected computer which only I will have access to. Your personal details will be further protected by the use of a pseudonym. **Please rest assured that you will not be able to be identified in any subsequent reports or publications. None of your personal details will be shared with anyone.**

What are the benefits and risks of taking part?

The risks will be in your comfort in disclosing personal information to me. Please be assured that I take confidentiality very seriously, and will send you all the information pertaining to you so you can add, clarify or delete sections before being included in the study. Whilst there are no immediate benefits to taking part in the study, it is hoped that the research will contribute to a new way of envisioning education with the needs and desires of disabled people at its heart.

Will I be recorded, and how will the recorded media be used?

The audio recordings of your interviews during this research will be used solely for analysis, and only I will have access to these. When the project is completed, the audio recordings will be destroyed. Unless you specify this as your chosen method, no video recordings will be made during this research.

What will happen to the results of the project?

The results of the research project will be held in the University’s library, on the 2nd floor of the Western Bank library from September 2018. (University Library Western Bank University of Sheffield S10 2TN). I will send each participant a copy of the published

study, if requested. **Data collected during the research project might be used for additional or subsequent research, but none of your personal details will be included.**

Who is funding the project?

The project is being funded by the Economic and Social Research Council, UK.

Who has ethically reviewed the project?

This project has been approved by the Education Department's ethics review procedure and is in accordance with the policies and practices of Sheffield University.

Who can I contact for more information or if I have any concerns about the process?

You can contact myself, as the lead researcher, on: jndaniels1@sheffield.ac.uk or my supervisor, Professor Dan Goodley, on: D.Goodley@sheffield.ac.uk
Telephone: +44 114 222 8185

What if anything goes wrong?

If you wish to raise a complaint, you can contact Professor Dan Goodley at the above address and telephone number. If you feel that your complaint has not been dealt with to your satisfaction, you can contact Tracey Earnshaw, the University's Registrar and Secretary, on: T.A.Earnshaw@sheffield.ac.uk, or telephone 0114 222 8115.

Thank you for your consideration.

INTRODUCTORY EMAIL

Dear Disability Research mailing list user,

My name is Julia and I am a PhD student at the University of Sheffield. I warmly invite you to participate in a new research project to share your experiences of higher education. The title of the project is, 'Interrogating ableism: exploring the psycho-emotional consequences of neoliberal ableist education' and I wish to gather personal accounts of how you, as a disabled person, see schooling, college and/or university. This is open to both those who are currently in education, and those recently (10-15 years) out of an educational setting.

You can tell these stories in whichever format is the most comfortable for you. As a disabled person myself, I prefer to take the added 'thinking time' of using email to write my story; you may prefer a diary composition, poetry, or spoken methods such as Skype. You may prefer more visual ways of presenting your narrative, such as photography, drawing or video. Stories will also be welcomed from those who use the support of other people to facilitate typing.

However you choose to tell your stories, what I'm looking for is personal reflections on how you felt about your experiences within your educational institution and the unique ways that it shaped you. For example, what do you think are the goals or aims of education? What do the terms 'ability' and 'success' mean to you? What are the pressures brought about by the focus on achieving 'academic success' for individual learners? The purpose of sharing these stories is to open up a space for the exploration of educational policy and practice around the world, and to question the efficacy of current approaches.

If you think you would like to know more about this project and would like to get some more information about it, please get in touch with me at jndaniels1@sheffield.ac.uk. If you wish to raise any concerns or complaints about this research, you can contact my supervisor, Dan Goodley on d.goodley@sheffield.ac.uk.

Thank you for taking the time to read this.
Yours hopefully,

Julia Daniels

ETHICS APPROVAL



Downloaded: 14/09/2015

Approved: 22/07/2015

Julia Daniels
Registration number: 140130278
School of Education
Programme: PhD in Education

Dear Julia

PROJECT TITLE: Interrogating Ableism: Exploring the Psycho-emotional Consequences of Neoliberal Able Education

APPLICATION: Reference Number 004107

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 22/07/2015 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 004107 (dated 07/07/2015).
- Participant information sheet 1011109 version 1 (07/07/2015).
- Participant consent form 1011112 version 1 (07/07/2015).

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely

Jayne Rushton
Ethics Administrator
School of Education

Article

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Disabled Mothering? Outlawed, Overlooked and Severely Prohibited: Interrogating Ableism in Motherhood

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Abstract

The ideology of motherhood precludes disabled people in various ways: sometimes outlawing it completely, in the case of enforced or coerced sterilisation; sometimes condemning it through the sanctioned removal of children and/or adoption; and at other times complicating it severely through lack of access to accessible goods and services that all mothers require to function in their day-to-day lives—such as pushchairs/prams, baby-changing equipment and baby-wearing apparatus. Ableism, “compulsory able-bodiedness” (Campbell, 2009; McRuer, 2013), will be used as an interrogative tool to aid in the ‘outing’ of the ‘able’: to tease out the values and principles undergirding this exclusionary perception of motherhood. As such I will be drawing on autoethnographic material, in conjunction with a Studies in Ableism (SiA, Campbell, 2009) approach to analyse the bypassing of disabled mothers and to suggest tentative ways forward. In the UK 1.7 million parents identify as disabled (Morris & Wates, 2006) and perhaps many more would do so if there were no fear of censure (see, especially, Booth & Booth, 2005; Llewellyn, McConell, & Ferronato, 2003; Sheerin, 2001; Swain, French, & Cameron, 2003) and their requirements need to be recognised, heard and provided for in the consumer market. The following article will articulate how disabled mothers are barred from the sacred hallow of motherhood, and delineate the need for the media, governmental organisations and marketing corporations to address their culpability in this blatant discrimination.

Keywords

ableism; disability; ideology; motherhood; normativity

Issue

This article is part of the issue “People with Disabilities: The Overlooked Consumers”, edited by Anita Borch and Kirsi Laitala (Consumption Research Norway—SIFO, Norway).

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1. Introduction

There exists an astounding disparity in knowledge about the reproductive health of disabled versus non-disabled women; virtually nothing is known about the number of disabled women of childbearing age, or their rates of fertility, pregnancy birth and abortions....This state of affairs should come as no surprise: “If research pursuits reflect social values, it makes sense that a society that has long ignored the gender role of women with disabilities has invested little effort in understanding their potential for love, partnership and motherhood” (Gill, 1996, p. 189, as cited in Prilleltensky, 2003, p. 22).

Although the actual numbers of disabled mothers in the UK is difficult to establish, it is true to say that we are a growing number, with a spending power of over £200 billion per year (Scope, 2018). There are many factors which *disable* a person according to normative criteria—energy fluctuations, physical embodiment, narrow societal definitions of cognitive capacity, the limited ability of society to communicate using sign language or Braille—and some, although not all, can be partially relieved through greater social access and inclusion. The social imaginary, however, that disability in and of itself must surely prevent a disabled woman from exercising her human right to become a mother often operates at the unconscious level of society’s collective genealogy. It manifests itself in the lack of provision of adequate goods and services to ensure smooth transitions into motherhood for many disabled women. This points to a residual undercurrent of ableism in the arena of reproductive liberty. The association with eugenics (see Frederick, 2014) has prevented this view from being explicitly recognised, but the regularity of routine screening practices for pregnant women has ensured that the reverence of ‘perfected’ ableness is alive and well. The following article hence, will probe why it is that disabled mothers may be discouraged from entering motherhood; how this takes place; and with what effect. I will draw on a number of resources to do this—my autoethnographic data as a disabled first-time mother; analysis gleaned from a review of theoretical literature to reflect the on the implications of mothering ideology as it relates to disability; and a strong orientation to the insights gained from studies in ableism (SiA). There have been many studies carried out, particularly in an Australian context, exploring the explicit outlawing and prohibiting of disabled mothering (for notable examples see Booth & Booth, 2005; Frohmader & Ortoleva, 2012; Steele, 2016; Tobin & Luke, 2013; Zampas & Lamačková, 2011). What I aim to do with this piece is to bring to the fore the implicit, the nuances—the microaggressions and internalised ableism, or what Campbell (2018, p. 25) terms as “ontoviolence”—the harm inflicted onto one’s very *being*—of the non-recognition of disabled mothers, reflected in the absence of adequate supports and provision (Pendo, 2008). My investigation here is two pronged: firstly, the objective is to ‘out’ the ‘able’, to articulate the values embedded within the ideology of motherhood and to what extent these are ableist; and secondly to investigate the more subtle pressures many disabled women experience to refrain from reproducing. The contribution of this research to the field, therefore, is to analyse the combination of motherhood and disability in the light of ableism theory.

There are differences in the use of the term ‘ableism’ across different contexts. My usage of the term follows Fiona Kumari Campbell (2009) and Dan Goodley (2014). Campbell (2014, p. 84) identifies:

Ableism as a mentality and practice is inherently narcissist. As a practice ableism demands an unbridled form of individualism, which is preoccupied with self-improvement and corporeal enhancement, and struggles with the reality of illness, disability and misfortune.

Gregor Wolbring (2008) describes ableism as a favouring of abilities, and the eternal othering placed upon those who apparently do not possess these socially prescribed ‘essential’ attributes. Ableist normativity treats disability as a state of exception, meaning that disabled people have to be treated as Other, as separate, and as deviant. Disabled people, thus, are by and large dealt with as an afterthought in society, and their needs are not met with alarming regularity. SiA reaches into the very foundations of disablism, which here is defined as discrimination against people due to actual or presumed disability (Goodley, 2014), to interrogate the roots of this oppression. As Campbell (2017, p. 8) states:

Ableism is deeply seeded at the level of epistemological systems of life, personhood and liveability. Ableism is not just a matter of ignorance or negative attitudes towards disabled people; it is a trajectory of perfection, a deep way of thinking about bodies, wholeness and permeability. Bluntly, ableism functions to “inaugurat[e] the norm” (As cited in Campbell, 2009, p. 5).

In other words, ableism serves to cast “normative shadows” (Overboe, 2007, p. 27) over human ways of being, an ethereal feeling that “one is constantly being judged according to different [and unstable] criteria of normality”. The race for perfection, in this light, is marked as being futile and essentially *unproductive*. The project of ableism I aim to develop in this article is to unmask the values undergirding the ideology of motherhood (ableism’s production) and to analyse how we as a society reinforce these values (ableism’s performance). Following on from Goodley (2014) and Campbell (2009), my aim here is to use the assumption of able-bodied and able-minded

motherhood to shed light on the beliefs, principles and standards underpinning the infeasible articulation of the 'ideal mother'. My intention is that by naming and explicating this figure we can come to expose the ableism lurking within it.

2. Methodology

I became disabled at age 19 through a road traffic accident which caused a traumatic brain injury, broken neck and permanent loss of feeling and movement in my right arm. The impact caused a collapsed lung, and the incubation procedure resulted in a paralysed vocal cord. I first became a mother on the 12th of August 2016, and am in the third trimester of my second pregnancy. I recorded my autoethnographical experiences of my first pregnancy and early motherhood in the form of field notes. My experiences of trying to negotiate these normatively oppositional identities, in conjunction with a firm grounding in disability studies and SiA, is used to strengthen my critical positionality and shed light on the discriminating practices of motherhood. A theoretical literature search was used to select, summarise and analyse the breadth of literature available on mothering, mothering ideology, intensive mothering and disabled mothering. The literature was then ordered thematically and by source (for example, autoethnographical material from disabled mothers; studies carried out by non-disabled researchers, etc.). This was then used to focus the specific research questions that, in my opinion, remain unanswered by previous studies. These questions are related to the exclusionary reverence of motherhood and to what extent this precarious approval is ableist:

1. What is it specifically that is valued in motherhood, and in what ways are these values ableist?
2. How do we as a society uphold and reinforce these values?
3. How can the study of ableism be used first to expose then to challenge and break down these stifling structures in order to forge a path for more creative mothering practices?

For the purposes of this article, the resulting analysis rests on an unfaltering bias, influenced by my positionality and as such omits many important perspectives such as the experiences of mothering older children and disabled fatherhood. These could of course be directions for future studies. Whilst I acknowledge that various impairments will have differing needs, I refer in this article to all disabilities regardless of their nature. The article is intended to be a theoretical reflection on the potential psychological and emotional position of disabled mothers in western society pursued with an ableist lens.

3. Ableism's Production: The Configuration of the 'Good Mother'

What can the study of abledment (Campbell, 2018)—the assumption of ablebodiedness—tell us about mothering? The ideology of mothering in its dominant narrative parallels neoliberal configurations of the ideal citizen (De Benedictus, 2012; Goodley, 2014; Fritsch, 2017; Lupton, 2012) and at the same time reinforces and demands conventional depictions of women. Ableism infiltrates this idealised version; it is clearly and strictly articulated, and symbolised in both explicit and covert ways. My research into the ideology of motherhood (Daniels, 2018) suggests that the 'approved' mother holds a number of valued characteristics: physical dexterity; fast pace; endless energy; emotional, mental and physical stability; and is self-contained, independent and autonomous. Therefore, in the light of ableist and normalised values, it leaves other ways of recognising ideal mothering to be downgraded—kindness, love, support, tolerance, acceptance, interconnection and cooperation—aspects of mothering that I would argue are to be championed, and do not rely on ableist rankings.

There is a long list of 'shoulds', 'always' and 'musts' in the definition of a good mother that many women in the western world have absorbed from media, government slogans, healthcare paraphernalia and their social networks. As Arendell (2000) identifies, the ideology of intensive mothering has morphed the collective social and personal expectations of mothering from being a 'good enough' mother into being an exceptional one (Green, 2015). It is not considered enough to be acceptable or satisfactory; mothers are pushed to be outstanding. This configuration of mothers is tied specifically to the excesses of ableism, pushing at its borders; to be exceptional, outstanding, and thus inherently *not* normal. The seduction of normativity loses its power here as the pressures of compulsory able-bodiedness spiral out of control.

Disabled women, in the above light, are set up in the social imaginary as an antithesis to the ideal mother and citizen, as an example of what not to be. This disablism rests upon a number of problematic assumptions, namely that disabled women are sure to have risky pregnancies, produce disabled (read: unworthy) babies, be a burden on the state, and be unquestionably incapable parents (Campion, 1995). The disablism inherent in these

assumptions has been challenged extensively elsewhere (Blackford, 1988, 1990, 1999; Crow, 2003; Malacrida, 2009; Prilleltensky, 2004; Thomas, 1997). The opening section of this article will consider the treatment of disabled mothers through pregnancy and early motherhood and reflect upon the potential internalising of ableist values resulting from this.

4. The Medicalisation of Pregnancy and Early Motherhood

The assumption of a normatively working, non-disabled maternal body is rampant in the ideology of motherhood, resulting in the infuriating lack of provision for maternal bodies who do not conform to these standardised ideals. Through the side-lining and societal disengagement with disability issues, many experts do not know how to adequately treat pregnant disabled women. This leads some doctors to treat the pregnancy in an “alarmist way” (Campion, 1995, p. 136). The lack of appropriate access to, for example, examination tables and other perinatal facilities (Tarasoff, 2017) for some women enacts a substantial barrier to their care. As Frederick (2017, p. 79) notes, the assumption that disabled women cannot or should not have babies, in conjunction with the project of normalcy, mean that the unique needs of disabled mothers are often rendered invisible. This misrecognition results in the market provision of products, goods and ‘expert’-driven advice manuals to be chronically underdeveloped for this population (Pendo, 2008). The prizing of bio-medical normalcy (Frederick, 2017) and the deep-rooted devaluing of disabled existence mean that the opportunity to access suitable products aimed at, for example, enhancing children’s development is limited if the mother differs from the norm. Through the lens of ableism we can come to critique this failure.

The ableist gaze that follows many pregnant disabled women is a profound factor in influencing their confidence in performing mothering tasks. The compulsion towards enacting able-bodiedness is still an oppressive concern for me. The notion of internalised ableism was a significant factor during my pregnancy, and left me with a deep feeling of trepidation.

3rd February 2016. Motherhood is an enchanting, captivating prospect, suffused as it is with tenderness and warmth, and I was deeply excited about it. I felt the flutter of delight thinking about the tiny life that was growing inside me. And yet this was marred by feelings of anxiety: how would I cope with a baby with, effectively, one functioning arm? All the mothers on advertising campaigns or in the media are able-bodied, and they seem to go about this role with a gracious ease. I felt that I needed to be as ‘able-bodied’ as I could, masking and hiding my disability. I feared that if I asked for help, I would be discovered as an incapable mother before the baby was even born, bringing attention to myself and inviting the scrutinising eyes of social services. So I pretended, I passed, I masked. This turned a potentially positive experience into the start of a downward emotional spiral. In a sense, the only real risk came from the lack of adequate support in my environment, and the anxiety of surveillance—both attributable to living in a disablist world.

Women in the UK and other western countries have been shown that there are certain ways of preparing for childbirth that are “culturally appropriate, morally underpinned and socially acceptable” (Miller, 2005, p. 31). Pregnant women are expected to give their trust, and thus a large amount of their lives (and the life within them), over to medical professionals. Whilst I acknowledge that there are many people working within the medical profession who are sensitive to the needs of disabled people, much more needs to be done to ensure that treatment is delivered appropriately and respectfully. The relinquishment of power to medical professionals has significant concern for disabled women as this is a profession, broadly speaking, which has systematically and uniformly negated their bodies.

23rd March 2016. I was desperate to be seen to be avoiding risk, to gulp down and seal off the treacherous reservoir of fear inside me that was threatening to engulf me within its depths. Nevertheless, the medical appointments during my pregnancy were always teamed with pointed looks at my hand, to which I felt—not angry, not a proud disabled woman, but a wave of shame. Every time this happened I could feel my face burning, as if my arm had brought dishonour to my body. This was feeding my anxiety and perception of myself as irresponsible, incapable and inherently ‘not normal’.

The desperation with which I wanted to be seen to be avoiding unnecessary risk—as if by my very embodiment I am already a ‘risky’ subject—is an occurrence noted elsewhere in the literature (for example Walsh-Gallagher et al., 2012; Crow, 2003). My narrative here shows how powerful and seductive notions of normative motherhood can be. The flush of pleasure that I got from the rare times that I conformed to the restrictive mothering role in my early experiences of motherhood eased my anxiety and tranquilised me. The need to prove myself as a responsible ‘normal’ mother is often overwhelming and utterly exhausting, which reflects the need to develop a more expansive ideology of motherhood that empowers the needs of a diverse society, one that does not seek to

include disabled people within exclusive “and individualised relations of neoliberalism” (Fritsch, 2015b, p48) but instead seeks to embrace interdependency and connection. Through the sometimes stealthy, sometimes explicit employment of biopolitics on pregnant women, they are highly encouraged to vet their actions through a process of stringent self-regulation, propelled by a plethora of expert guidance—the governing of the self. But the most ingenious fact of this method of biopolitics is that pregnant women are enlisted in the effort of self-regulation as a way to prove ‘responsible’ motherhood. So insidious is the ableism around motherhood, and so sneaky is it of infiltrating our collective genealogy that we actually come to aspire to normative forms of mothering—often without realising it.

5. The Ableist Biopolitics of the Pregnant Body

Pregnancy, once considered a natural state, has now come to be characterised in the western world in the language of ‘risk’ (Cahill, 1999). The pregnant woman, thus, has lost her identity and autonomy as far as the foetus is concerned. The body of the pregnant woman itself is considered dangerously unstable and chaotic, with permeable boundaries, in a cultural milieu where static and bounded states are considered ideal (Lupton, 2012). The woman’s previous identity as a woman with needs and wishes of her own is gone, replaced with her being solely a vessel for the unborn child. She no longer exists, other than to be highly monitored as a potential risk. The pregnant woman is portrayed as weak and irresponsibly influenced by her carnal desires, and so she must pay unyielding attention to the advice of the medical and psychological experts. This state of Foucauldian self-regulation is the epitome of biopolitics (Rose, 2006). Maternal responsibility and rationality are here intertwined, emphasising individual responsibility for risk management—thus denying or minimising state obligations. Nikolas Rose (2006) surmises that we are entering an era of ‘perfected’ human abledness, wherein we are experiencing “a qualitative increase in our capacities to engineer our vitality, our development, our organs and our brains” (Rose, 2006, p. 4). This molecular vision of life opens up serious debates around the kinds of societies we want to create, and who is given value within those societies.

6. Interrogating the Foetus

Many research studies (for example Campion, 1995; Kallianes & Rubinfeld, 1997; Prilleltensky, 2004) have focused on the assumption that children born to a disabled mother will inevitably be disabled themselves or suffer the effects of the maternal disability, which rests on wider assumptions about disabled people and their place in society. The foetus has come to be aesthetically judged as viable and healthy, or as defective. The advances in prenatal testing have positioned certain foetuses as being “less worthy of the privileges of citizenship than other foetuses, and as liabilities to society” (Lupton, 2012, p. 336). Prenatal tests, once reserved for ‘high-risk’ pregnancies, are now carried out on a regular basis (Parens & Asch, 2000; Suter, 2002). The axiomatic decision to offer a termination if the foetus does carry the genetic markers of disability is in itself an ableist assumption. It is ableist in the way that society urges us to think and feel that disability is a state that should, if at all possible, be cured or eradicated; in the way that non-disabled life is prioritised and held above all other ways of being; and in the way that this assumption makes disability and disabled people in many crucial ways invisible.

The presumed need and desire to have prenatal testing points to the hegemonic perception that the life enjoyed by disabled people is inherently not as good, not as (normatively) productive, or not as worthy of life enjoyed by non-disabled people. As Saxton (2000) asserts, it also assumes that raising a disabled child will necessarily be an unwanted burden on mothers. There is little discussion of the potential joy, creativity or insight that disabled children may bring to this world. This suggests a need for pregnant women whose foetuses are found to have the genetic markers of ‘abnormality’ to be counselled honourably about the possibilities and potentialities of having a disabled child. The whole issue of prenatal testing, it can be argued, underscores and predetermines future attitudes to disability in an intrinsically negative way. It conspires with the medical view of disability: that if there is a way to prevent it, then we as a society have a moral and ethical responsibility to do so. In making the argument against prenatal testing Adrienne Asch (2003) points out a number of misconceptions about life with a disability: firstly, that in subscribing life with an impairment to inherently unfavourable conditions, it fails to take into account the impact that discriminatory attitudes and social practices (which can be changed) have on the disabled child’s life. Secondly, that it places “unwarranted emphasis” (Asch, 2003, p. 318) on the breadth of a person’s opportunity range, rather than concentrating on the meaningful decisions that can be made within that range; and thirdly, that ‘lacking’ a “capacity, skill or experience” (Asch, 2003, p. 318) is fundamentally a bad thing. Rather, this ‘lack’ can and does lead to innovative and productive ways of being. This way of viewing disability—as intrinsically and unequivocally detrimental to one’s life and one’s opportunities—is constitutive of the narrow-minded, prejudiced medical model of disability, a model that most disabled people and their advocates are exasperated by.

7. Ableism's Performance—Debilitating Stereotypes

Disabled women are deemed as being always dependent on others, therefore they cannot have others depend on them as they would be incapable of providing for their needs (Malacrida, 2009; Shaul, Dowling, & Laden, 1985). This assumption arises from the prosaic and clichéd depictions of disabled women as being asexual, dependent and therefore unequivocally unsuited to the role of motherhood, in its dominant narrative (Malacrida, 2009; Parchomiuk, 2014; Fritsch, 2015a, 2017). This is problematic in a number of ways; firstly, by identifying certain individuals and methods of parenting as ideal, it narrows and restricts other means of motherhood by identifying them as deviant and devalued. It is also dependent on a very limited view of caring, and assumes that all caring is physical in nature. This gives little credence to the acts of love, support, guidance, fostering of social awareness, acceptance, and morality. The restriction characterised by such a precarious definition calls for a nuanced view of the responsibilities of a parent; as Campion (1995, p. 140) states: "It could be that a responsible parent is one who ensures the welfare of her child by orchestrating whatever combination of support is required". She goes on to remind us that "(t)he physical needs of a baby are very different to those of a 10 year old. It is important to remember that dealing with nappy changing and feeding is a very short-lived stage of a relationship that might last for fifty years" (Campion, 1995, p. 141). This assumption, Campion states, is also reliant upon the notion that dependency is a "negative, helpless state" (Campion, 1995, p. 139). Dependency can be seen, rather, as an intrinsic element of all relationships in society and the realisation of this helps to bind us together. In this light, dependency and *interdependency* is not something we should shy away from but something we want to promote.

8. Breaking the Spell: Exposing Ableism

Studies (Malacrida, 2009; Prilleltensky, 2004; Thomas, 1997) have shown that there is often a positive ontological reframing when a disabled woman transitions into motherhood. The new-found status as a valuable mother, blossoming life into this world, in many instances symbolises a fresh change for women previously categorised as little more than a drain on the system. However, there lurks beneath this view a stranglehold of normalcy when the disabled mother fights against all odds to be, or to be seen to be, the 'perfect (self-contained) mother'. The mother who can do it all herself, with no help from anyone else (Fritsch, 2017). Studies (Prilleltensky, 2004; Thomas, 1997) have shown that there is often increasing pressure for a disabled mother not to ask for services or supports that would assist their mothering through a debilitating need to be perceived as 'capable'. This points to the damaging effect that professional scepticism can have on the self-worth, and resulting feelings of ability, of the mother. If the mother feels constantly undermined and humiliated, the consequences upon her self-esteem can be devastating. This form of psycho-emotional disablism (Reeve, 2012; 2014) is cruel and exhausting, and is a colossal drain on the limited energy resources of any new mother. In my experience, this has led to me feeling that I am unequivocally unable to cope with the responsibilities of motherhood, and therefore unable to reliably handle my own child, as I have tried to illustrate in my narratives. I feel the grip of this sensation starting to weaken as I explore and expose the ableism tied up in constructions of mothering that emphasise the physical dexterity of mothers.

However temporarily uplifting and empowering these narratives of choosing motherhood are, some studies (Callus & Azzopardi-Lane, 2016; McFarlane, 2005; Prilleltensky, 2003; Thomas, 1997) show that the experience of pregnancy and early mothering for disabled women is treacherous, requiring inordinate amounts of iron will and determination. The emotional labour of acting in defiance of family, friends and professionals is a crucial factor threatening to obscure and dampen the transition to motherhood for many disabled women. Researching the phenomena of disabled mothering has shown me that I am unfortunately not alone in the hostile responses from certain individuals in the medical profession. Studies of disabled pregnant mothers-to-be confounded this perception (see Crow, 2003; Prilleltensky, 2004; Skinner, 2011; Thomas, 1997). All of these studies show that disabled women are routinely objectified, marginalised, and treated with a toxic mixture of scorn, disbelief and distaste. Often disabled mothers are seen as selfish and reckless for bringing a life into this world when it is a common misconception (Baum & Burns, 2007; Prilleltensky, 2003; Wates & Jade, 1999) that they can barely look after themselves, however true or false that might be.

As Liz Crow (2003, p. 3) states in her presentation to the Department of Health around the provision of maternity services to disabled women:

When I'm on the outside needing to get in, what I see is a lot of people missing the point. My being on the outside is not about me, but about them. It's about the assumptions, and the ways of working that exclude whole groups of people. Tackling that exclusion, by introducing inclusive practice, is not about making 'exceptions' or meeting 'special needs' (It is only when they are not provided for that needs become special). In maternity services,

inclusion is about achieving a start where I can primarily be *pregnant*—not because I am the same as non-disabled pregnant women but because my needs are just as integral to planning and working practice as theirs.

Crow's point here is that, as a disabled woman, she is largely not provided for in maternity services and thus rendered invisible, but as soon as she alerts her presence to them she becomes a 'problem' in need of 'special' needs. In her own words, she becomes "centre stage" (Crow, 2003, p. 3). We can apply her statement, 'it is only when they are not provided for that needs become special' to a range of institutions and social practices, and it has specific salience here. If society was open to the diverse range of people who mother I may have felt more secure of my impending motherhood as the range of adaptive solutions may have been more readily accessible. Sadly, as it presently stands, disabled women are not on the list of society's idea of 'good' mother material. This is a stark reminder that reproductive liberty does not have the same significance for every woman. Admittedly there are concerns about the impact that a loss or malfunction of a limb or energy fluctuations has on a person's ability to mother, as my narrative shows. But how much of this is due to practical concerns (which in a truly inclusive society would be provided for) and how much can be attributed to internalised ableism—the product of living in a disablist world?

This is where the provision of adequate and affordable support comes in. Access to goods and services in the consumer market can be a lifeline for many disabled women, and can provide additional networks of support in a society that prizes self-reliance. Where this support is lacking it can cause detrimental effects to the psycho-emotional well-being of the mother, as exemplified in my own experience:

12th June 2016. I pondered and planned in careful and considered detail throughout my pregnancy, purchasing the softest clothes and the latest gadgets; but everywhere I looked there were obstacles lying in wait. Pushchairs are not designed with the disabled body in mind. I trawled through websites and browsed countless shops, but the responses were the same—'we don't have anything for you I'm afraid'. Nappy changing also created a wave of fear; one thing that parents will have to perform relentlessly, and there are very few effective solutions on the market to aid someone like me. Baby-wearing, which I was keen to do, was only possible with someone else to help attach her to me. It became conspicuously clear that I would not be able to mother independently and that concerned me greatly. I have never felt more disabled than I did during my pregnancy. This sense of trepidation and unease perpetually gripped my throat, tight, strangling my joy. I desperately tried to think positive and to hold on to the wisps of happiness and excitement that this new life was bringing, but I also felt it was my responsibility to be realistic and practical. With this in mind, I searched endlessly, and fruitlessly, for gadgets, devices, anything that may make my life as a mother smoother and more manageable. It became clear that if you don't fit into the narrow stereotype of a mother-to-be then there is nothing for you.

9. Adaptations and Accommodations: A Lifeline, or Coercion to Ableist Normativity?

Although there are a number of adaptive solutions available to aid disabled parenting, these are scarce and often difficult to access. They are also often beyond the financial means of the families who could benefit the most from them. I enlisted in the private help of a professional doula, but as she was unfamiliar with disability issues she was unable (or unwilling?) to help. According to a survey carried out by the Disability, Pregnancy and Parenthood International (DPPI) in 2011, more than 70% of disabled parents were not aware of any sources of information or adaptive equipment (DPPI, 2015). Additionally, the results from this survey indicated that both social care professionals and disabled parents "struggle to find appropriate resources on disabled parenting" (DPPI, 2015, p. 1), and that the quality of the support that they did receive was inadequate. One notable exception to the lack of resources is the organisation Through the Looking Glass (2018) in the US, which was founded in 1982 to help families in which a child, parent or grandparent has a disability or health-related issue. A similar organisation, Remap.org, is available in the UK, creating adaptive solutions for disabled people throughout their lives. Another site, DisabledParent.net, is largely aimed at wheelchair users, thus ignoring or side-lining other disabilities. The site features products that disabled parents have made themselves, reinforcing the idea that disability is the responsibility of the individual, akin to the medical model that many disabled people have worked hard to dispute. The DisabledParent.org is another similar example. The website points out things to look for when shopping on the mass market for equipment that can be adapted to suit individual needs, such as prams/buggies that are lower to the ground for ease of access etcetera. It does not give any suggestions for specific equipment and, again, suggests that this is the responsibility of disabled parents themselves. The website actually states:

Parenting positively changes the lives of disabled individuals. It presents an opportunity for a *normalized* life where you get to parent like your nondisabled peers. Your journey comes with great satisfaction for being able to surmount the challenges of parenting with a disability. (Disabledparent.org, 2017, italics added).

This conceptualises a stated desire for parents to *overcome* the disabling barriers of a hostile society through their own actions by mimicking non-disabled people. All sites reviewed assume that there will be someone else in the house with you to do some baby care tasks, contravening the strong cultural imperative of self-sufficient mothering. Compensatory measures set disability as being the fault of the individual, and as having nothing to do with a restrictive society. In effect, the search for adaptive solutions promotes the disabled mother's assimilation into ableist norms.

10. Concluding Remarks

According to Shildrick (2002, cited in Mitchell & Snyder, 2015, p. 4), certain countries in the western world “are making tremendous strides towards the formal integration of the rights, obligations, and expectations of normative citizenship” for disabled people. However with the case of reproduction and disabled motherhood in mind, these changes are not paralleled by a dramatic enough shift in public attitudes to disability. By engulfing disabled people within the depths of normative citizenship, it is becoming increasingly difficult to “recognise (our)selves outside of the values, needs and desires preferred by the market” (Mitchell & Snyder, 2015, p. 4). We must therefore recognise the danger inherent in being subsumed, *gratefully*, into the seduction of compulsory ablebodiedness with its punitive principles, instead of challenging the very foundations that this disablism rests upon.

As I alluded to earlier, many mothers are complicit in perpetuating the restrictive and prohibitive ideal of the ‘good’ mother. Faced with overwhelming depictions of themselves in the social imaginary as inadequate and deficient, it can take extraordinary levels of emotional and physical labour to try to perform the idealised mother role, and even more to resist and refuse such limiting narratives and forge new connections and resources for enacting motherhood. And so it is that countless disabled mothers, myself included, push themselves to achieve an able-bodied articulation of idealised motherhood. Through the lens of ableism, we can see that, by trying to conform to standardised notions of the ‘good mother’, many disabled mothers are trying to pass or morph ableist ideals when actually we need to break free from this suffocating oppression. All compensatory measures set the ‘problem’ of disability up to be as individual issue, one that needs to be corrected by assimilating disabled people into ableist norms. I read about disabled women trying—and being praised for—doing mothering in normative ways, in spite of the emotional and physical energy that this takes. These stories tend to deny the unique knowledge that disabled mothers have, incorporating *interdependence*, cooperation and connection. The very notion of ‘overcoming’ disability is a dangerous preoccupation, as it concerns itself with disability disavowal. This splitting off of disability in an effort to return to a historically unstable version of ‘normality’ denies the importance and validity of owning a disabled existence. Future research is essential to address how products, services and supports could be expanded and energised in a way that absorbs and reflects the needs of a diverse society, *inclusive* of disabled mothers.

The atypical and creative ways in which disabled women perform motherhood are not recognised, provided for or even acknowledged in the consumer market of products and advice targeted at mothers. Bravery, courage and tenacity should be found in the ways that those three simple words: ‘I need help’, are asked in a society that demands and enforces independence in mothering tasks.

On the surface opponents to disabled mothering argue that the mother (inevitably) could not cope with the demands of childrearing, and that there is a fear that the ‘biological defects’ could be transmitted to the child. This, they say, would constitute irresponsible mothering. But I sense there is something deeper at play here. I argue that by admitting us in to the sacred hallow of motherhood, this threatens to destabilise the social construction of disability as inherently less than, incapable, *invalid*. The Mother is an esteemed figure in society, and conflating the two stereotypes further weakens the precarious binary. It engenders a deep-seated anxiety in “those who are able to broadly align themselves with the illusory standards of the psychosocial imaginary” (Shildrick, 2012, p. 32). Disabled motherhood creates fear because it exposes the instability and the futility of aspects of individualism and the incessant race for perfection that it is grounded upon. It exposes as futile the hundreds of products on the market aimed at ‘making you a better person, inside and out’. It does this by dispelling the assumption of the relegated Other—the disabled—to which able-bodied society can compare themselves and feel relieved. Capitalist society needs to continue to promote the insinuation that all of us are never good enough in order to further the plethora of goods and services in the consumer market to aspire to perfected, unstable, and unreachable ‘norms’.

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Conflict of interest

The author declares no conflict of interest.

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About the Author



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***‘Already Doing It: Intellectual Disability and Sexual Agency’* by Michael Gill. Minneapolis, University of Minnesota Press 2015, ix + 255pp., US \$26 (paperback); UK £18 (paperback) ISBN 978-0-8166-8297-3**

Should sexual citizenship depend on IQ levels? Should the sex lives of people with the label of intellectual disabilities be regulated and subjected to surveillance? By extension, who should be deemed worthy of assessing this apparent prerequisite for engaging in sexual relations? How does the social and cultural construction of intellectual disability as naïve and sexually deviant influence institutional and educational practices? Should civil rights be awarded to only particular idea(l)s of human beings? ‘Already Doing It: Intellectual Disability and Sexual Agency’ is a promising and insightful book that invites us to enter into dialogue around these compelling topics with thought-provoking results. The central goal of this book is to provide counter-stories to the ones dominantly accepted – that sex between, or sexual relations of any kind, amongst people with intellectual disabilities is risky, inappropriate, wrong, inadvisable and improbable. This book also opens up a space to ask essential questions about power, authority and resistance. I was excited at the prospect of reading this work, anticipating engaging and lively debate. I was interested as to how Gill would employ a combination of Crip theory and a feminist standpoint to an analysis of legal casework, educational policies and film critique with the intention of illuminating entrenched hegemonic practices around what many consider to be a taboo subject – intellectual disability and sex. This book unquestionably delivers on this point; Gill’s use of a feminist framework here encourages an ease with ambiguity, demands critical questioning of taken-for-granted practices, raises awareness and facilitates analytical reflections on educational policies and legal processes.

The book begins with an honest admission of Gill’s first experiences with disability. He confesses to feeling a sense of disgust and fascination as a child at watching a mother feed her intellectually disabled daughter who was roughly the same age as him. He felt ashamed, as an adult, because he realised that this staring was a result of his learned fear and mistrust

of disability. This admission for me ignites a feeling of vulnerability and humbleness pertaining to his shame, and indicates the wealth of knowledge that we can learn from disability –about the responses to it, and the potentialities embedded within it. Gill is honest, too, about his prejudiced and superior attitude whilst working in a sheltered workshop wherein his assignment was to help people with the label of intellectual disability to find work. He outlines his unquestioned compliance (and a prime example of asserting able-bodied privilege) with the task assigned to him of regulating and preventing sexual behaviour, although he admits that this was outside his remit of duties. In this, he acknowledges that he failed to reconcile his own burgeoning sexual feelings with those of the adults in the workshop, separating his own desire to explore and potentially connect with others as a ‘natural’ feeling; and the potential for the pairing or grouping of intellectually disabled adults as dangerous, inadvisable and unthinkable. This disavowal highlights just one example of the injustice of relegating the particular knowledge that intellectually disabled people have to the margins, effectively silencing them, “erasing the embodied knowledge and unique epistemology about life...further illustrat[ing] the denial of disability as a worthwhile state to occupy” (Gill, 2015:3). The presumed lack, based on unspecified assessment of capability and intelligence, of a ‘reliable’ voice with which disabled people can articulate their desires, wants and needs, resurfaces at many points throughout the book. At times this is challenged by Gill, but I feel that a lot more could be made of this occurrence of ableism (or disablism, in UK terms). My feeling is that Gill could have addressed this point further, particularly in relation to the legal casework he analyses. It is important to note here, some discrepancies in terminology that may confuse readers working from other contexts. For example, the term ‘ableism’, in Gill’s definition, is defined as: “... in its most broad interpretation reflect[ing] discrimination or oppression of disabled people, which can take the form of denial of rights and access and the perpetuation of stigma, hatred and othering”; in UK terms this would generally be described as *disablism*.

The first chapter of the book examines questions of consent and notions of competence in which Gill traces the apparently well-known legal case of Kalie McArthur and Robert Harris. He weaves the threads of legal casework, journalistic representation and theory to provide an astute analysis of the ways in which the application, unconsciously or consciously, of ableism intersects with racism, classism and sexism (Gill, 2015:23) to produce prejudiced reactions. Gill does not offer a definitive opinion on the case, rather focusing on the way that McArthur, as a person with an intellectual disability, is continuously portrayed as the vulnerable,

innocent victim deserving of pity and Harris, despite being a minor, is vilified as an unruly, ‘hormone-filled’ predator. McArthur, notably, was not given the opportunity to share her thoughts on her experiences, a fact which Gill only briefly comments upon.

Chapter two concentrates on the materials used to deliver sex education to individuals with intellectual disabilities in the US, and contemplates whether a discourse of pleasure can and should be incorporated into sex education. Gill analyses the regulation and control around sexual behaviour, particularly enacted in group homes, as to which sex acts are permitted and which are deemed ‘risky’ and inappropriate. This is further evidence of the paternalistic and rigid boundaries that are applied to the lives of people with the label of intellectual disability. To counter this, Gill advocates a “feminist approach on teaching pleasure” (p.50) that would expand the qualification for sexual citizenship and the eligibility to *be* sexual. Sex education, Gill asserts, needs to include a discussion of alternative modes of sexual relations and activities to counter the narrow and limiting assertion that only heterosexual couplings are allowed and validated, and needs to move beyond the sole categories of risk prevention and harm reduction.

The next section of the book is devoted to a discussion of reproduction and the propensity to which solitary masturbation, as an alternative to engaging in sexual relations with a partner or multiple partners, is heavily promoted as a ‘safe’ and acceptable form of sexual expression for individuals with intellectual disabilities. The degree to which sexual activity is regulated and controlled for in this population, in comparison with non-disabled people, is starkly highlighted at many times in the text. The eugenic practices of forced sterilisation are used as an example of sexual ableism that occurs with troubling regularity, justified by the assumption that intellectually disabled parents would not have the capacity to care for the resulting offspring. In his analysis of Hollywood films around this subject, Gill highlights that children are shown to be removed from their parents due in part to the stereotype of intellectual disability as being child-like, inadequate, helpless and in need of constant support and supervision. This is an example of the ways in which popular media reinforces and perpetuates damaging stereotypes.

Chapter five of the book troubles the notion that parenting should be limited to able-bodied, heterosexual parents only. Gill uses an example drawn from a photography exhibition created by Rickie Solinger and Kay Obering to illustrate this occurrence in practice. The exhibition, called ‘*Jasmine’s World*’, focuses on the instances of ‘lack’, informed by the creator’s innate

prejudice, of parenting skills displayed by the (intellectually disabled) mother in particular. This illustrates how disabled people are regularly required to demonstrate and perform 'super-human' qualities to prove that they are indeed worthy of the same rights afforded to non-disabled people without question. This underscores the "arrogant perception" inherent in the assumption that only certain (white, heteronormative, able-bodied, middle-class) people should be allowed the privilege of parenting.

Through his use of secondary material, I feel that Gill loses a sense of immediacy and richness gained in other studies on this topic. Liddiard's work (2014) in particular benefits from an evocative poignancy that is gained from her use of narratives as a methodological strategy. The inclusion of personal stories from people with the label of intellectual disabilities would make *Already Doing It* a phenomenal resource that emphatically tackles the discourse of sexual ableism in this context. Nevertheless, this is a well-articulated, thought-provoking book that is highly recommended for students with prior knowledge and interest in the concepts and theories of critical disability studies, Queer and Crip theory. It is also a must-read for educational policy makers in the field of intellectual disability and sexuality.

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