

Article

Disabled Mothering? Outlawed, Overlooked and Severely Prohibited: Interrogating Ableism in Motherhood

Julia N. Daniels

School of Education, University of Sheffield, Sheffield, S10 2GW, UK; E-Mail: jndaniels1@sheffield.ac.uk

Submitted: 23 April 2018 | Accepted: 15 October 2018 | Published: 31 January 2019

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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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). (Prilleltensky, 2003, p. 22)

1. Introduction

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 disability, which here is defined as discrimination against people due to actual or presumed disability (Goodley, 2014), to interrogate the roots of this oppres-

sion. As Campbell (2009, p. 5, as cited in 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”.

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 unflinching 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 able-bodiedness—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’.¹

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 Crow, 2003; Walsh-Gallagher, Sinclair, & McConkey, 2012). 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, p. 48) 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

¹ Excerpt from a personal diary entry with a final reference to Malacrida (2009).

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 (Parsons & 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 (Fritsch, 2015a, 2017; Malacrida, 2009; Parchomiuk, 2014). 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:

The 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, emphasis 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, pro-

vided 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'.

Acknowledgements

The author would like to extend thanks to the Economic and Social Research Council (ESRC) who funded her PhD. Grant code ES/J500215/1.

Conflict of interest

The author declares no conflict of interest.

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About the Author



Julia N. Daniels is a fourth year PhD student at the University of Sheffield. Her research interests include the study of ableism (after Campbell, 2009) particularly within education and motherhood. She is also interested in feminist autoethnography, and communication standards and diversity within speech. Julia is a married mother of soon-to-be two girls, and currently lives in the south of Spain.