

The Work of Disabled Identities in Intimate Relationships

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INTRODUCTION

The oppressions experienced by disabled people in their sexual and intimate lives have long been overshadowed by wider rights for their rightful place within civil and public life (Shakespeare, Gillespie-Sells, and Davies 1996). The consequences of this, Shakespeare (1999, 54) argues, have been the marginalisation of disabled people's sexual politics and the omission of the "personal and individual dimensions of oppression." Feminist authors within disability studies have challenged these important omissions, and have at the same time located gender and other social categories within analyses of disability (Baron 1997; Thomas 1999). Much of this critical scholarship has been through writing openly about their own embodiment, intersectional identities, and lived experiences of impairment (see Morris 1989; Wendell 1996; Thomas 1999), causing what Sherry (2004, 776) called a crucial "deconstruction of the public/private divide."

While social model orthodoxy holds the psychological "as epiphenomenal, diversionary, and potentially misappropriated in the buttressing of pathologising accounts of disablement" (Watermeyer 2009, iii), feminist authors—markedly Thomas (1999), and later Reeve (2002)—have argued for the inclusion of the psychological and emotional dimensions of disability and impairment within disability studies (see also Goodley

2011). For example, in her social relational model of disability, Thomas (1999, 60; emphasis added) redefines disability as "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 well-being." Thus, "disability" is reimagined to have political, material, economic, structural, emotional, intimate, and personal dimensions. Redefining disability along these lines contextualises that "the oppression disabled people can experience operates on the 'inside' as well as on the 'outside'" (Thomas 2004, 40); or, as Reeve (2004, 84; original emphasis) articulates, "operates at both the public and personal levels, affecting what people can *do*, as well as what they can *be*."

Psycho-emotional disablism is defined by Thomas (1999, 60) as "the socially engendered undermining of emotional well-being." Reeve (2004, 86) proposes that this form of social oppression occurs through "the experience of being excluded from physical environments" (which, she argues, instigates a feeling of not belonging); through routine objectification and voyeurism perpetrated by (but not exclusive to) non-disabled others; and through internalised oppression, which she defines as when "individuals in a marginalised group in society internalise the prejudices held by the dominant group" (Reeve 2004, 91). Thus, psycho-emotional disablism is

a relational form of disablism embodied through experiences of “hostility or pitying stares, dismissive rejection, infantilisation, patronising attitudes, altruism, help and care on the part of non-disabled people” (Goodley 2010, 96), which “frequently results in disabled people being made to feel worthless, useless, of lesser value, unattractive, a burden” (Thomas 2006, 182).

Building upon existing knowledge of psycho-emotional disablism, particularly its potential impact within the personal, intimate and sexual spaces of disabled people's lives, I present findings from a relevant empirical study that explored disabled men and women's lived experiences of sexuality and intimate relationships. To clarify, my use of the term “intimate relationship” refers to a (non-commercial) shared intimacy with another person, which my informants identified as significant and a source of sexual, physical and/or emotional intimacy. The doctoral research, which took place in England between 2008 and 2011, examined disabled people's management and negotiation of their sexual and intimate lives, selves and bodies in the context of ableist cultures where they are, as Brown (1994, 125) states, assigned the paradoxical social categories of “asexual, oversexed, innocents, or perverts.” This article draws upon the sexual stories of 25 disabled people, detailing a thematic analysis of their accounts of intimate relationships that reveal the—often routine—carrying out of considerable emotional work (Hochschild 1983), as well as other forms of (gendered) work, such as sex work (Cacchioni 2007). By making visible their work of “telling, hiding, keeping up, waiting, teaching, networking and negotiating” (Church et al. 2007, 10), I explore the ways in which informants' work was shaped by their lived experiences of gender, sexuality, impairment and disability. Crucially, I critically question such work, suggesting that, while it was often strategically and consciously employed to manage competing intimate oppressions, for the most part, the requirement of informants to carry out forms of work within their sexual and intimate lives constituted a form of psycho-emotional disablism (Thomas 1999).

Learning to Labour: Emotional Work and Disability Performance

Church et al. (2007, 1) state that “complex invisible work is performed by disabled people in every day/night life.”

In their research on disabled employees' experiences of corporate settings, Church et al. (2007, 1) uncovered multiple kinds of work that employees routinely utilised within the workplace in order to “stay corporately viable.” 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). Similarly, Wong (2000) has documented the multiple forms of (emotion and other) work employed by disabled women in reproductive and sexual health care; she states that “work has become an umbrella code that encompasses both the barriers women face and the agency they exercise in dealing with them” (2000, 303). Likewise, Goodley (2010, 92) has identified the *performances* disabled people are expected to give: “disabled people learn to respond to the expectations of non-disabled culture—the demanding public—in ways that range from acting the passive disabled bystander, the grateful recipient of others' support, the non-problematic receiver of others' disabling attitudes.”

However, while the psycho-emotional dimensions (Reeve 2002; Thomas 1999) and “work” and “performances” of the “disabled” identity have been explored within disability studies (Church et al. 2007; Goodley 2010), the concepts of “emotional work” and “emotional labour” have seldom been applied to disabled people's experiences (Wilton 2008). The little empirical work that has taken place has related to work settings and public spaces and systems (see Church et al. 2007; Wilton 2008; Bolton and Boyd 2003; Wong 2000). To clarify, “emotional work” and “emotional labour” are terms coined by Arlie Hochschild (1983, 7) to represent the “labour [which] one is required to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind to others.” Emotional labour is mostly required within employment settings and refers to the “management of feeling to create a publicly observable facial and bodily display . . . [that] is sold for a wage and therefore has *exchange value*” (Hochschild 1983, 7; original emphasis). In contrast, “emotional work” or “management” are forms of work that are required in private settings, such as the family or home, and which have “*use value*” (Hochschild 1983, 7; original emphasis). “Emotional work,” then, is a better-fitting conceptual framework for explorations of disabled people's lived experiences of their intimate relationships.

My definition of the term follows that of Exley and Letherby (2001, 115; emphasis added) and refers to the "effort and skill required to deal with one's own feelings and those of others within the *private* sphere."

Emotional work takes many forms and serves a variety of functions; for example, work can be on or for the self (Hochschild 1983); on or for others (Exley and Letherby 2001); have both positive and negative consequences (Wilton 2008); and be both a collective and individual labour (see Korczynski 2003). Predominantly, women, "as traditionally more accomplished managers of feeling" (Hochschild 1983, 11), have been found to carry out the majority of emotional work in the private sphere (Strazdins 2000)—largely because they take prime responsibility for the emotional well-being of other family members (Devault 1999). Identifying this work serves important functions. Early work by Blumer (1969, 148) argues that identifying the "invisible" work carried out as part of our daily lives can act as a "sensitising concept," in that it can thrust previously neglected activities (e.g. childcare, caring for relatives) onto the public agenda. Furthermore, Devault (1999, 62) suggests that identifying the customary emotional work that takes place within family life is invaluable towards providing "fuller, more accurate accounts of how family members work at sustaining themselves as individuals and collectivities," an understanding that, she argues, provides "an essential foundation for equitable policy aimed at enhancing the well-being of all citizens."

Before outlining the research methodology, I must stress that by utilising the concept of emotional work (Hochschild 1983), I am not individualising, pathologising or psychologising disabled informants' emotional experiences. The psycho-emotional, psychological and now psychoanalytic (see Goodley 2011) aspects of disability remain contentious within disability studies for fear that they encompass a return to early "individual, medical, bio-psychological, traditional, charity and moral models of disability" (Goodley 2011, 716), which "locate social problems in the head and bodies—the psyches—of disabled people" (Goodley 2011, 716). On the contrary, through deconstructing informants' work I highlight the very social, cultural, political and material processes through which their work is produced.

RESEARCH FINDINGS AND DISCUSSION

The Strategic Work of Staying

In keeping with western conceptualisations of coupledom, all informants who had been in an intimate relationship before ($n = 21$) reported it as having considerable *benefits*. For example, the intimate relationship was narrated as a "safe space" from a range of oppressions, discrimination and prejudices experienced in the "outside world," and as a powerful means to challenge ableist discourses of disabled people as sexless and as not being "prospective" partners (Gillespie-Sells, Hill, and Robbins 1998). It was further described as a space where gender and sexual selves could be confirmed and (re)built. For example, Rhona,¹ a 21-year-old recently-single woman with a congenital impairment, said: "being in a relationship is a constant reassurance in my worth as a person and a woman." Therefore, the intimate relationship could serve as a space to embody (gendered) desirability, contradicting dominant cultural representations of disability and the impaired body as both degenerated (Shakespeare 1999) and monstrous (Shildrick 2002).

However, a common theme centred on informants residing in intimate relationships for reasons beyond (romantic) feelings for a partner, and exacerbated by a disabled identity within an ableist heteronormative sexual culture. For example, Robert, a 26-year-old wheelchair user with congenital impairment, said that "having" or "being with" an intimate partner was an important symbol to *others*:

I've discussed with my [disabled] best friend, how we need a girlfriend to show "Look a real girl likes me. I have sex with her and we are in love—I must be ok. world." (Robert)

Robert's strategy openly acclaims a sexual identity and thus, he feels, "puts right" the dominant ableist assumptions of asexuality and sexual inadequacy cast upon impaired male bodies (Shakespeare, Gillespie-Sells, and Davies 1996). This indicates that, as DeVault (1999) suggests, merely surviving oppression is a form of work in itself.

However, for others, residing in intimate relationships, even where informants had expressed they were often unfulfilled and/or unhappy, was a means through which to avoid oppressive dimensions of dominant

sexual cultures; for example, “being single” once again (and thus losing many of the benefits listed above); being rejected on the “dating scene” (because of disability and impairment); and negotiating the (often risky) disclosure of disability and impairment to prospective partners. Notably, this strategy required the employment of considerable emotional work (Hochschild 1983):

Because of my disability I thought “oh well, I need to stick with this because I might not find anybody else.” . . . (Shaun)

Because I am disabled, it gives you the worry about getting a girlfriend, you hold onto it for dear life, until it's like flogging a dead horse and that's no good for anybody. (Tom)

The accounts of Shaun, a married man who acquired spinal injury at the age of 11, and Tom, a single man with congenital physical impairment, show how their choices to stay in (former) unfulfilling intimate relationships were shaped by the potential difficulties of finding a partner as physically impaired men within a gendered sexual culture that privileges hegemonic masculinities—from which disabled men are largely excluded (Shakespeare 1999). Further, I suggest that phrases like “sticking with it” and “flogging a dead horse” emphasise their *emotional* efforts. For example, Shaun said that in previous intimate relationships with (non-disabled) women he had painfully and silently worked past partners' infidelities because he desperately “wanted to be in a relationship and wanted to have a partner.” Therefore, Shaun had to employ an acute form of what Hochschild (1983, 33) calls (emotional) “mental work,” whereby he not only had to perform the appropriate “display work” of a contented partner (Hochschild 1983, 10), but carry out significant “mental work” on his emotional self to really *feel* like—or *become*—a contented partner (Hochschild 1983, 6).

Another common chapter in many informants' stories ($n = 23$) related to the way that they felt that a relationship, love and sex were “out of reach” as a disabled person—a form of sexual oppression internalised through ableist constructions of disabled people as lacking sexual agency and opportunity (Siebers 2008). For those with congenital impairments, such thoughts were reported as having been internalised from a young age and had often been confirmed by (usually, well-meaning) family

members; for example, telling them “not to get their hopes up.” This was narrated to have substantial impact upon sexual self-confidence and esteem (and thus constituted significant sexual oppression) and supports the notion that psycho-emotional disablism can be at its most acute when carried out by known agents (Reeve 2002). Graham, a 52-year-old single male who acquired physical impairment at age 20, told of how he had been in intimate relationships with women to whom he was not attracted and did not like because he saw them as the “only opportunity” to have a relationship; but also because these relationships provided an (albeit, temporary) solution to his isolation and loneliness:

I didn't like her . . . my attitude was entirely “I've got no choice . . . she likes me for some reason and it's her or nothing.” . . . Never liked her; never fancied her. I didn't like her touching me. . . . It's horrible but there's no other option. You either just spend your life entirely alone or try and be with someone who's willing to be with you. (Graham)

Graham spoke at length of the multiple emotional performances that such relationships required. For example, he talked about performing emotional displays of sincerity, honesty and authenticity when “pretending” to like these intimate partners. The abhorrence Graham reveals in the above account shows that these situations required routine surface acting (Hochschild 1983). Rather than *becoming* an intimate partner through what Hochschild (1983, 33) defines as “deep acting” or “mental work,” the emphasis for Graham was upon imitating the “correct” emotional behaviours synonymous with love, intimacy and affection. To add context, Graham reported experiencing significant marginalisation and isolation, which many disabled people experience: he lived alone, said he had no real friends or family, and rarely went out. Using Thomas' (1999) social relational model of disability, Graham's marginalisation and feelings of loneliness sit at the nexus of structural, psycho-emotional and material dimensions of disability: he dropped out of university upon acquiring impairment because, he said, his institution could not cater adequately for a disabled student; a lack of qualifications combined with having to negotiate a disabled identity within an ableist labour market and capitalist economy led to both long-term underemployment

and unemployment, which has in turn impacted upon his social mobility and his access to material resources (see Oliver 1990). Graham described these structural oppressions, then, as having significant impact upon his self-esteem and confidence (especially with women), denoting to him the feeling that he did not belong in, or did not have the attributes to attain, a meaningful intimate relationship (see Reeve 2004).

"Women's Work"

The carrying out of emotional work could also be couched within particular forms of gendered work, most notably "sex work" (Cacchioni 2007, 299). In her exploration of heterosexual women's perceptions of their sexual problems, Cacchioni (2007, 301) found that women carried out "sex work," which she defines as "the unacknowledged effort and the continuing monitoring which women are expected to devote to managing theirs and their partners' sexual desires and activities." Of my informants, while it was not uncommon for both men and women to openly question their role as a sexual partner, particularly their ability to sexually "fulfil" partners (in ways fitting with heteronormative sexual practices), three women (of 10 in total) in the sample took it further and were explicit about the ways in which they consciously (sex) "worked" to "compensate" non-disabled male partners in order to "make up" for having an impaired body.

For example, Jenny, aged 64, who acquired spinal injury at the age of 11, talked about how she would "get involved in every aspect of sex you could think of, any way that was pleasurable to him [her ex-husband]." She said: "I would put myself out to give him that pleasure even if I wasn't getting any that particular time." Jenny carried out this sex work in order to not be perceived as "sexually inadequate" by her husband in comparison with his non-disabled ex-wife. The sacrificing of her own sexual pleasure shows the "entwined nature of embodied and emotional performance work" (Wilton 2008, 367). Similarly, Lucille, 36, who became tetraplegic at age 23 (when she was already married), told how following her injury she had offered her non-disabled husband multiple chances to be unfaithful: "I felt so bad about not wanting sex that I kept telling him to have an affair." Lucille and Jenny's actions cannot be separated from their identities as disabled women; their sex work is indicative of the low sexual self-esteem that is widespread

among disabled women generally (Gillespie-Sells, Hill, and Robbins 1998), and more likely to occur in women with severe impairment who "tend to be furthest away from cultural constructions of ideal feminine beauty" (Hassounah-Phillips and McNeff 2005, 228).

However, while Jenny and Lucille talked very matter of factly about their sex work, acknowledging that their labour was *conscious* towards embodying desirability for their non-disabled male partners, most women in the sample spoke about hiding bodily difference during sexual encounters—but seldom questioned such practices. Hiding was described by women to take place through a complex (yet remarkably routine) organisation of duvets, bed sheets, clothing, and lighting in a bid to both perform and embody the highly gendered role of the seductress. I suggest that this hiding can be seen as a *private* form of "aesthetic labour," which Wolkowitz (2006, 86) defines as "employers' attempts to make the body more visible in customer service work through a focus on the body's aesthetic qualities." Carrying out some form of aesthetic labour, whether private or public, is, undoubtedly, a likely reality for *all* women due to the ways in which heterosexist and patriarchal constructions of femininity instil, as Bartky (1990, 40) suggests, an "infatuation with an inferiorised body" against which women will always feel inadequate. However, for the disabled women in my research this was undoubtedly compounded by (impaired) bodily difference being wholly intolerable within the rubric of the normative body. Actively hiding the body in this way affirms that disabled informants fear that their departure from bodily normalcy can be a basis for rejection (even from intimate partners), and thus the need to "pass" (and all of the work that goes with this) remains.

The Emotional Work of the Care Receiver

Emotional work through surface acting (Hochschild 1983) took place most explicitly when informants received care from partners within intimate relationships. Of 10 informants who said they regularly received care and assistance from a partner, all said that this arrangement could be a site of tension that required emotional management (see Morris 1989). Many narrated care from partners as something they had to "put up with," in that partners did not carry out tasks correctly or in preferred ways. Even though this could be a central source of

frustration—and often anger—it was a situation where the disabled partner had to show incredible tolerance and grace, and be grateful through surface acting (Hochschild 1983), often when they fervently felt the opposite. Thus, in order to manage the “feeling rules” present within the caring relationship (Hochschild 1979, 552), rules that “govern how people try or try not to feel in ways appropriate to the situation,” disabled informants had to show emotions that were “appropriate” for those receiving care (see Morris 1989). Importantly, this extensive emotional work was crucial towards simultaneously maintaining functioning care relationships alongside intimate partnerships.

For example, Helen, who is 21 years old and has a congenital and progressive impairment, emphasised the extensive emotional work required in having to “teach” her new partner how to care, which involved “smiling through” what she called “bad care” while he learned her preferred way of doing particular caring tasks. She warned that this meant always appearing “tolerant” and “grateful,” for fear that “he could just tell me to get stuffed!” Often these difficult dynamics increased when the disabled partner had an increasing level of need; for example, on becoming ill or through impairment progression. Gemma, a 42-year-old lesbian who has immunity impairment, told how a cancer diagnosis meant she had to be cared for full-time by her then-partner. Gemma spoke of the ways in which she had to manage her partner’s anxiety around her cancer, even when she was the one who had it. Notably, this emotional work had to be carried out at a time of significant personal emotional anxiety, emphasising the ways that emotional work is often on or for others (Exley and Letherby 2001). Some informants ($n = 4$) said that receiving care from a partner affected the way in which they dealt with conflict within their intimate relationship. Thus, caring was often conceptualised as something a non-disabled partner could offer, rather than a requirement. As such, it was also something that could be denied. For example, Robert, age 26, and Terry, age 20, who both have a congenital physical impairment, said that they avoided conflict or arguments with a partner, as a strategy to ensure continued care:

If an argument arose, could I really defend my point even if I’m right, but then ask for help knowing they’re annoyed with me? (Robert)

With a girlfriend, I know that I can’t be easily irritated by things they do, because I’ve got to rely on them to

help. In the past I haven’t had an argument with a girlfriend unless it’s been at a time where I don’t need them for any help. (Terry)

Robert and Terry’s actions to purposefully avoid conflict are evidence that receiving care from an intimate partner can mean having to consciously mediate and manage these complex relationships through very careful strategies. Such strategies undeniably required various forms of emotional work, management and performance—notably, tolerance; “submission”; graciousness; the assessment of when and when not to assert oneself; and the general management of a very problematic set of power relations, in order to continue to receive the required care or assistance from intimate partners.

DRAWING SOME CONCLUSIONS

The stories (re)told throughout this article have uncovered the work and labours of disabled men and women within multiple locations of their intimate relationships. Throughout their stories, informants cast *themselves* as active subjects, revealing their diverse roles as teacher, sex worker, negotiator, manager, mediator, performer and educator. Paradoxically, much of the skilled emotional work disabled informants carried out is highly valued within western labour markets (Hochschild 1983), from which they are largely excluded. Irrespective, recognising and labelling the work of disabled people within their sexual and intimate lives is important. Firstly, doing so provides fuller, more accurate and inclusive descriptions of the complex ways that disability, impairment, gender and sexuality interact within sexual and intimate life—as well as of the potential psycho-emotional dimensions of such interactions. Secondly, by identifying informants as skilful managers of their intimate and sexual lives—regardless of the outcome or efficacy of their work—their labour challenges dominant ableist constructions of the disabled sexual identity and subjectivity as passive and lacking agency (Siebers 2008).

However, clearly evident within informants’ stories and in the analysis of their feelings was the extent to which they devalued their (sexual) selves, revealing the ways in which low sexual self-esteem and self-worth, feelings of inadequacy (in relation to heteronormative discourse), and low body confidence can be common parts of the disabled (sexual) psyche in ableist

heteronormative sexual cultures. Despite exercising a form of sexual agency as active “emotional workers,” then, the requirement of informants to carry out forms of work within their sexual and intimate lives, I argue, constituted a form of psycho-emotional disablism (Thomas 1999). For example, rather than overt transgressive resistance, much of the (invisible) work uncovered in this research was carried out largely through *necessity*—in order to survive; to be loved; to be human; to be included; to be “normal”; to be sexual; and to be valued. Thus, it is crucial not to underestimate the sizeable extent to which work was rooted in and thus indicative of the oppressive and inherent inequalities of ableist culture.

Further, analysis has shown that informants’ work was both located and produced at the intersections of disability, gendered and sexual identities, emphasising the value of appreciating relational and psycho-emotional dimensions of disability (Reeve 2002, 2004; Thomas 1999) when exploring the sexual lives of disabled people. The fact that much of informants’ work was routinely employed for the benefit of *others* supports Goodley’s (2010, 92) notion of disability performances that fit with “expectations of non-disabled culture.” Significantly, where emotional and other work did take place on or for the self, it extended only to emotional and/or bodily management; typically, either through a conscious and rigid policing (or hiding) of emotional responses or bodily difference—forms of work that seldom bought informants *pleasure* or personal fulfilment. For example, surface and “deep” acting within intimate relationships; engaging in forms of sex work; and providing “appropriate” performances of gratitude and gratefulness when receiving care, were markedly detrimental to a positive sense of (sexual) self in most cases and constituted a distinct form of psycho-emotional disablism that operated at a level which required informants’ complicity.

In certain spaces, typically gendered performances that affirmed dominant constructions of masculinity and femininity were offered; notably seen within the different strategies men and women employed to sexualise themselves, either in their own eyes or in the eyes of others. Thus, disabled male informants’ employment of forms of emotional work within intimate spaces challenges the idea of the male identity as privileged within emotional working (Hochschild 1983) and sheds

light on the ways in which alternative (non-hegemonic) masculinities interact with emotional work and labours. Moreover, women’s employment of normatively gendered labours such as sex work (Cacchioni 2007) and “private” aesthetic labour (Wolkowitz 2006) reveals how emotional work is rooted in their social and political positioning as disabled people and—as with the motivations of non-disabled heterosexual women—by normative notions of womanhood, femininity and (hetero)sexuality. This emphasises the similarities between the experiences of disabled and non-disabled women, who occupy analogous subordinate positions within heteronormativity and heterosexuality. It also illustrates—as other disabled feminists already have (Morris 1989; Wendell 1996; Thomas 1999)—the need for mainstream hegemonic feminism to be more inclusive of all types of women and thus broaden its contextualisation of the female experience that, while diverse, is unified by women’s suppression under patriarchy and male (sexual) power.

In sum, the analysis detailed in this article supports feminist contributions to disability studies—particularly those that have called for inclusion of the gendered and psycho-emotional dimensions of disability (Thomas 1999; Reeve 2004). Crudely, a “pure” social model analysis would simply not have bared the intimate, personal and gendered oppressions central to informants’ lived experiences. As Thomas (1999, 74) points out, rather than psychologising disabled people’s emotions, applying a (feminist) disability studies or social relational lens to disabled people’s emotional lives removes these from being “‘open season’ to psychologists and others who would not hesitate to apply the individualistic/personal tragedy model to these issues.” In this vein, then, revealing linkages between structural and psycho-emotional forms of disablism can actually serve to de-pathologise disabled people’s experiences in ways advocated by social model politics, at the same time as theorising and reframing disability in ways that best attends—most importantly—to the emotional well-being of disabled people.

NOTE

1. All informant names used within this article are pseudonyms.

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