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## Feeling disability: theories of affect and critical disability studies

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### ABSTRACT

This paper explores connections between affect studies and critical disability studies. Our interest in affect is sparked by the beginnings of a new research project that seeks to illuminate the lives, hopes and desires of young people with ‘life-limiting’ or ‘life-threatening’ impairments. Cultural responses to these young people are shaped by dominant discourses associated with lives lived well and long. Before commencing our empirical work with young people we use this paper to think through how we might conceptualise affect and disability. We present three themes; ontological invalidation in neoliberal-able times; affect aliens and crimp killjoys; disability and resistant assemblages.

### ARTICLE HISTORY

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### KEYWORDS

Theory; disability; affect; emotions; life; short lives

### Points of interest

- This article is sparked by the beginnings of a research project working with young people with ‘life-limiting’ or ‘life-threatening’ impairments (LL/LTIs).
- Too often, society treats people with LL/LTIs as tragedy cases requiring pity and sadness.
- People often respond to disability in deeply emotional ways.
- There has been a lot of research recently on emotions which is broadly termed affect theory but disability is often ignored.
- We seek to connect affect theory and disability research with reference to young people with LL/LTIs in ways that can capture the desires, hopes and ambitions of these young people, their families and allies.

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## 1. Introduction

This article explores the original offerings of affect theory to studies of disability and, as a way of exchange, the unique contribution of critical disability studies to theories of affect. Our interest in the latter has been elevated by the beginnings of a new research project, 'Life, Death, Disability and the Human: Living Life to the Fullest' (ES/P001041/1) funded by the Economic and Social Research Council, and seeks to forge new understandings of the lives, hopes, desires and contributions of children and young people with 'life-limiting' or 'life-threatening' impairments (LL/LTIs). With children and young people as our co-researchers, the project will be a space where disabled children and young people can tell new stories of disability; their own stories.

There is something instantly emotive around the idea of a child or young person living a short life. People are affected, often deeply, by the idea that a young person's life course is reduced through the presence of impairment. We know that cultural and individual responses to young people with LL/LTIs are significantly shaped through a plethora of dominant ideas and practices linked to idealisations associated with quality of life, human productivity and lives lived well and long. Young people with LL/LTIs appear to be at odds with the neoliberal imperatives of self-sufficiency, autonomy and independence. Their presence makes society feel for their predicament. In this article, we seek to contest these dangerous discourses with reference to concepts emerging from the inter-disciplinary fields of affect theory and critical disability studies. Because our project is in the early stages of fruition and empirical work is yet to start, we use this article as an opportunity to pause and to consider possible connections between theories of affect and critical disability studies.

## 2. Introducing theories of affect

There will always be debates about the extent to which we can generalise an intellectual space that is fraught with debate, tension and disagreement. The study of affect broadly hails a return to emotion and feeling including (although not exclusively) happiness, love, optimism, misery, contentment, guilt, bitterness, envy, humiliation, fear, grief, disgust, passion, psychic pain, desire, hope, shame, anger, imagination and optimism. Gorton (2007) observes that distinctions are sometimes made between emotion (a sociological expression of feelings) and affect (a physical response rooted in biology). Such a simplistic distinction is now generally avoided and we use affect and emotion interchangeably in this article to acknowledge that biology and society are firmly wrapped up with one another. As Gorton (2007, 334) puts it, 'feeling is negotiated in the public sphere and experienced through the body'.

It is a truism to suggest that we affect other people and are in turn affected by them. Yet the return to affect in social theory is a relatively new one, predicated

upon the idea that theorists have tended to sideline the emotional. Sociologists, for example, have always been preoccupied with discourse, culture and structure. These are, after all, some of the big-hitting leitmotifs of the discipline. A turn to affect asks us to consider those elements that have been ignored in favour of more public, measurable and structural indicators. Similarly, discursive psychologists have contested the individualisation of psychological ideas such as attitude, personality, resilience and emotion but have left the theoretical space with very little to say about the affective or the embodied. Emotions and embodied feelings need to be part of sociological and critical psychological thinking. The turn to affect is not simply about addressing a missing psycho-emotional dimension in social theory. Affect theory responds to the ways in which affects are mobilised by economic and cultural forces. Affect theories are interested in the ways in which contemporary citizens are 'thrown into a constellation of affections – which may have the quality of feeling necessary to our lives, but which may be both contingent and punitive' (Duschinsky, Greco, and Solomon 2014, 224). We come not only to know and perform ourselves (Butler 1999); we are also expected to know how to feel.

According to Wetherell (2015, 139), the humanities and psychological and social sciences are witnessing the emergence of various theories of affect that attend to the ways in 'which bodies are pushed and pulled in contemporary social formations, in the "engineering" of affective responses, and in how workers and citizens become emotionally engaged and affectively interpellated'. In their special issue on affect in the journal *Body & Society*, Blackman and Venn (2010) draw attention to the ways in which affect is felt at the level of the body but is always socially and culturally conditioned. Affects are felt individually, materially and physiologically but are always being reproduced by their entanglements with the social world. In their special issue of *Feminist Theory*, Pedwell and Whitehead (2012) consider the relationship between affect and feminist theory. They note that affect studies constitute an interdisciplinary space with often contradictory and oppositional takes upon the subject matter. What is clear, following Gorton (2007, 334), is that there is shared interest in the way 'feeling is negotiated in the public sphere and experienced in the body'. Foucault often figures in the bibliographies of affect theorists in the biopolitical constitution of the subject and subjectivity, and many authors share 'a concern with how power circulates through feeling and how politically salient ways of being and knowing are produced through affective relations and discourses' (Pedwell and Whitehead 2012, 116).

One of the most well-known affect writers, Ahmed (2004) is clear that we are subject to various affect economies in which bodies and emotions are shaped and stifled. We are increasingly witnessing an 'emotionalisation of society' (Pedwell and Whitehead 2012). Romantic love, for example, becomes known through dominant practices of Hollywood, psychotherapy and memes of social media. Nurture, affection and care are shaped through complex political, cultural and social economies. Think of the John Lewis (a UK department store) Christmas television adverts as explicit examples of the ways in which desire, care and family are played out – and

risk being prescribed – through the act of consumption.<sup>1</sup> Dan (first author), at this juncture, feels it necessary to shamefully confess that every Christmas, no matter how Scrooge-like he is feeling, he finds himself in bits, sobbing before his kids, as they look on at him with disgust. What can we say? Dan's a sucker for a bouncing dog, a lost snowman and a forlorn rabbit. As a key player in the affect economy, television is a successful exploiter of catchy emotions (Gorton 2007, 338); those feelings that spread contagiously through the workings of affect economies (and especially catchy in relationships of consumption). Ahmed's work displays a cynicism towards those social and cultural processes that threaten to affectively box people in: to become emotionally attached to particular kinds of object and subjects in the social world. The feelings we hold and express can (re)produce dominant social and geopolitical hierarchies and exclusions (Pedwell and Whitehead 2012, 120). In this sense, then, affect is always relational: and these relationalities take place between humans and non-humans, bodies and culture, individuals and society, and organic entities and machines (Fox and Alldred 2015). How we come to feel or emote is the consequence of our relationship with others. We affect others and they affect us. This leads Wetherell (2015) to conclude that affect is always distributed: we feel and emote in the relationships we have others.

The affective turn is also associated with some moves to put the psyche into the social (hence the idea of the psychosocial in critical social psychology). But this does not necessarily mean reinserting a pre-social psyche. For instance, Blackman and Venn (2010, 20) are interested in the kinds of idealised images of the body that shape affects: 'the kinds of fantasies and desires that might propel our investments, financial and corporeal with our bodies'. Affect is something that is performed and it is the idea of affective practice that Wetherell (2015) prefers over a choice of affect. Wetherell is a renowned discursive psychologist and so is interested in the ways in which discursive practices produce the effects of their actions. This understanding of affective practice resonates with the hugely influential work of Hochschild's (1983) emotional labour. This concept seeks to account for the assault on the self that occurs in response to demanding publics. 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 sense of the affective register being laid out through complex social and cultural relationships invites in the work of Hardt and Negri (2000, 2004), not least in their idea of biopolitical citizenship and immaterial labour. As Goodley and Lawthom (2011, 118) have articulated, Hardt and Negri shine light on 'the transformation of the labour process which has created a new proletariat through an emphasis on knowledge and affect (with the latter showing an increased weight of activities focused on health, education and social care) (Rustin, 2002)'. We are increasingly made to do work on ourselves – governance – and we do this through working the self and our relationships with others. This immaterial labour – knowledge, information,

communication and emotional reproduction – becomes the site through which we constitute our subjectivities, identities and ways of being with others. Increasingly, places that were formerly the remit of the private/personal (e.g. sexual relationships, families, households) are increasingly governed by public interventions, which seek to normalise their practices and create ideal national citizens:

These areas of affective/emotional/immaterial labour – which include the service industry, health and social welfare services, caring and maternal work – know no hours of work (beyond the 9 to 5 working day), are always labouring and in the process of becoming experts about themselves. (Goodley and Lawthom 2011, 118)

This centralising of subjectivity in the constitution of self and society will be all too familiar to students of Foucault. In addition, Hardt and Negri (2000, 2004) push this analysis further into a conceptualisation of affective labour as *the* labour of the postmodern proletariat caught up in the globalisation of an affect economy (or Empire as they term it; original emphases).

A turn to affect is also associated with a desire to recognise the materiality of the body – and the material relationships between human bodies and other non-human entities. This addresses the somatophobia that has been found in some transformative writings in queer, feminist and disability studies. This fear of the body can be traced back to the advent of these radical perspectives which, in part, politically responded to biological essentialism that viewed queer, disabled and female bodies as inherently abnormal. In contrast, recent theories of affect have focused on the extra-discursive. A common trope within the philosophy of materialism ultimately considers matter to be something that exists beyond human perception (Flynn 2017). Accepting the limits of discursive analysis has pushed many into what are now commonly known as new materialist theories (associated often with the appeal of writers such as Rosi Braidotti, Brian Massumi, Gilles Deleuze and Felix Guattari). Martin (2013) offers an anthropologist's reading of the materialist affect theory literature. She notes, borrowing from the work of Leys (2011, 437), that, at various times, affects are considered to be:

‘inhuman,’ ‘pre-subjective,’ ‘visceral’ forces and intensities that influence our thinking and judgments but are separate from these. Whatever else may be meant by the terms *affect* and *emotion* ... the affects must be non-cognitive, corporeal processes or states. (Martin 2013, 465; original emphases)

Materialist affect theorists seek to tune into the human as a visceral, embodied, emotive and corporeal creature. Too often in social theory there is an emphasis on reason, rationality and the linguistic. A positive of such a reading of affect is that we recognise the pre-social potentiality of a living body. A negative reading of this is that we are straying into the dangerous theoretical lands of the pre-social biological: a terrain exploited by some forms of psychological individualism and essentialism (see Billington's [2016] critique). We share Martin's (2013, S156) concerns when she states: ‘we need to ask whether one result of seeing the affects as biological phenomena is losing the insights that feminism can provide’. A more positive reading of the material potentiality of the body is provided by Deleuze

and Guattari (1987) – who position the body as one full of affective potential yet to be coded and stifled by strict cultural codes. Affect, in this sense, is a ‘material intensity that emerges via the “in-between” spaces of embodied encounters, circulating power not primarily as a mode of discursive regulation but rather as the potential to “become otherwise”’ (Pedwell and Whitehead 2012, 116). This vague language of DeleuzoGuattarian potentiality is given political purchase and conceptual clarity through the hugely influential work of Braidotti (1994, 2002, 2003, 2005, 2006, 2013). For example, her work on nomadic affectivity represents desire as outward bound and based on the human’s complex relations with a multiplicity of others, including non-human others. This reorganisation of desire – from the psychoanalytic desire for the things we lack to a desire for connections anew with other humans and non-human beings – is explained in part through our deeply technologically embedded global world which blurs ‘fundamental categorical divides between self and other; a sort of heteroglossia of the species, a colossal hybridisation which combines cyborgs, monsters, insects and machines into a powerfully posthuman approach to what we used to call “the embodied subject”’ (Braidotti 2005, no page). Put simply, then, Braidotti asks us to reveal the connections between humans, other humans and non-humans because through these relationships we might find major rearticulations of affect, emotion and feeling. This is the brave new world of the posthuman: a space and time where we find ‘non-unitary, radically materialist and dynamic structure[s] of subjectivity ... [expressing each] subject’s capacity for multiple, non-linear and outward-bound inter-connections with a number of external forces and others’ (Braidotti 2005, no page).

The human category of modern societies (especially in Western Europe and North America) has been one tied to the ethics and philosophy of humanism: a speaking subject, bounded and ordered, with clear distinctions of cognition/affect, reason/passion, rationality/irrationality or self/other. The posthuman is a reaction and an alternative to humanism and its associated prescribed, bounded and self-governing sovereign self. Affect is released from its binarised and othered distinction (as the opposite of cognition) as the human category itself is opened up as a distributed entity more in keeping with our contemporary techno-culture. Affect is not to be found inside human beings, but in the connections and relationships between humans and non-humans. In her early writings, Braidotti (2005, no page) was keen to emphasise a number of ways in which the posthuman condition is created:

- ‘Mutual inter-dependences and productive mergers of forces that give rise to creative becomings’ (here we like to think of the work of educational inclusion done between and amongst a group of disabled and non-disabled children in a classroom as they are assisted by a teacher and her assistants to work together as a group task).

- ‘Replacing the old subject formation with a notion of the subject as a cluster of complex and intensive forces – intensive assemblages which connect and inter-relate with others in a variety of ways’ (the disabled child is no longer a fixed subject but part of the assemblage already described).
- ‘An attack on identity. Not on any one identity, but on the very concept of identity’ (consider the ways in which a child is always becoming – never a fixed being – and use this same idea when thinking about humans more generally).
- ‘Avoiding references to the paradigms of human nature (be it biological, psychic or genetic essentialism) while taking fully into account the fact that bodies have indeed become techno-cultural constructs immersed in networks of complex, simultaneous and potentially conflicting power-relations’ (it is no longer possible to talk of national boundaries, friendships or activist organisations in the same way as it was 20 years ago before the advent of social media).
- ‘A non-unitary vision of the subject that endorses a radical ethics of transformation, thus running against the grain of contemporary neo-liberal conservatism, but it also asserts an equally strong distance from relativism or nihilistic defeatism’ (a grounded sense of working together as an assemblage, impossible to pinpoint where the collective begins or ends, a celebration of many connection points, of numerous affective possibilities).

Braidotti writes that ‘a non-unitary subject proposes an enlarged sense of inter-connection between self and others, including the non-human or “earth” others, by removing the obstacle of self-centred individualism’ (2005, no page). Our affects – and what we desire – are enacted through our mutual interdependencies and assemblages rather than as manifestations of inherent humanist emotions.

Fox and Alldred (2015) set up new materialist analyses as being interested in social production rather than social construction; especially in relational networks or assemblages of animate and inanimate entities. Materiality is plural, open, complex, uneven and contingent especially if viewed from a DeleuzoGuattarian perspective (Deleuze and Guattari 1987; Fox and Alldred 2015, 400). Hence:

- Bodies are always relational as are other material, social and abstract entities with no distinct ontological status other than produced through their relationships or assemblages.
- We replace the idea of human agency with the Spinozist notion of affect: meaning simply the capacity to affect or be affected. So affects are always becoming and this refers to a change in the capacities of state of an entity.
- We attend to the production of assemblages, which are constantly becoming as they territorialise (stabilising an assemblage) or de-territorialising (destabilising an assemblage) (Fox and Alldred 2015, 401).

Deleuze and Guattari (1987) suggest that we map the assemblage and find gaps between its rigid lines that offer lines of flight and the emergence of smooth spaces (for moments of de-territorialisation). As Youdell and Armstrong (2011, 145) put it:

Striated space can be thought about as the binary, hierarchical, and normative meanings of spaces and their possibilities and impossibilities ... Striations are the deep scores or grooves cut by the rigid lines of the assemblage, defining and constraining meaning and practice. The smooth spaces against which these are contrasted are not distinct spaces, but are moments and sites of possibility when and where the assemblage and its striations might be disrupted or deterritorialized ... A line of flight might allow us to trip out of the striations in which we are caught to skate on the smooth plateaus between, even if in doing so we slip into or begin to grind out yet another striation.

Smooth spaces are associated, then, with de-territorialising over-coded striated assemblages. Youdell and Armstrong (2011) encourage us to think about school. Consider the over-coding or the striations of schools. Note those un/written rules that pervade. Think too how in these school assemblages children are sifted, selected and coded in affirmative ways (gifted and talented) or, in other cases, coded in limiting ways (Special Educational Needs and Disabilities). We will return to materialist analyses of affect later.

The rise of emotion and feeling is also having huge impacts on the human and psychological sciences, specifically neuropsychology. Billington (2017), for example, draws in the work of the critical neuroscientist Antonio Damasio, whose focus on affect, feeling and emotion has not only expanded conceptualisations of the cognitive to include emotion but also emphasised the impact of the environment on the brain. Billington (2017, 5) insists that these new affective neuroscientists are interested not in the minute detail of neurons firing but in 'lifting /the neurological or psychological veil to reveal the latest political challenge posed to social and education inclusion'. Here Billington's work is closely aligned to the work of Ahmed and others who are interested in moving beyond 'the "inside out" model of psychology, and the "outside in" model proffered by sociology and anthropology' (Pedwell and Whitehead 2012, 123). Affect is necessarily complicating, then, because it seeks to challenge these well-worn distinctions between interior and exterior worlds. How we feel is closely connected to our place in the world and many theorists of affect want to keep this dynamic relationship between self/other, body/society and psyche/culture, developing new vocabularies for understanding these complexes.

Thus far, in this article, we have considered some of the theoretical considerations and analytical trajectories within the field of affect studies. Our sense is that much is to be gained by critical disability studies engaging with this work and this is especially the case from our perspective as we start a new research project that works alongside young people with LL/LTIs and their families.

### 3. Sparking our interest in affect: our study

Our interest in theories of affect has been generated by the beginnings of a new research project. We can gauge the values of any society by considering how it treats those people who are the most marginalised. Too often disabled young people find themselves on the outskirts of society. This is especially the case for one group of disabled young people. We know much about the deaths of young people with life-limiting or life-threatening impairments (LL/LTIs) but relatively little about their lived lives. This invisibility could be detrimental to their social and emotional well-being and mental health, and that of their families/carers and allies. Our research seeks to forge new understandings of the lives, hopes, desires and contributions of disabled young people with LL/LTIs. This will permit us to think differently about how society understands life and death, and will deliver forms of co-produced knowledge that will be useful to academics and to a host of civil society organisations, professionals and communities that are also seeking to value short lives and respect death as part of the human condition. Our inquiry is a flagship project of the Institute for the Study of the Human at the University of Sheffield.<sup>2</sup> The project began in April 2017 and finishes in April 2020.

According to the national charity Together for Short Lives, LL/LTIs considerably shorten children and young people's life expectancy. There are around 49,000 children and young people with LL/LTIs in the United Kingdom, and these rates are increasing year on year. Young people with LL/LTIs are living longer than ever before, yet we know little of their lives, particularly from their own perspectives. This lack of knowledge is due to the marked absences of this unique group of disabled young people from public imagination and broader culture. Young people with LL/LTIs have been omitted from much academic research; are seldom explicitly written into public policy; are often excluded from disability communities and disabled people's own movements; and have their voices dominated by professional perspectives within palliative (end-of-life) care teaching, education and training (see Runswick-Cole, Curran, and Liddiard, 2017). Whilst there has been work in the palliative, nursing and medical worlds on LL/LTIs, very little of this work has included or speaks from young people's own perspectives. Consequently, critical questions subsist around personal, relational and collective well-being. This project is timely given that our previous research showed that disabled young people and their families/carers and allies experience significant exclusion and discrimination; exclusion which is currently exacerbated through severe austerity in the United Kingdom. Therefore, with young people alongside us as our co-researchers, and working in partnership with leading disability/LL/LTI organisations (Purple Patch Arts, DMD Pathfinders, Good Things Foundation, Muscular Dystrophy UK Trailblazers), we will explore the lives of young people with LL/LTIs as they experience and understand them, with the aim of making their lives visible. Young people with LL/LTIs and their families will tell their own stories through multi-modal engagement with innovative art-making and narrative approaches.

Working with our Community Research Partners and Expert Impact Partners we are co-designing impact activities which ensure that research findings are applied and utilised in real-life settings and thus are relevant, transferable, accessible and transformative outside academia. We propose that this impact serves to improve the social, emotional and mental health and well-being of young people with LL/LTIs, and their parents/carers and wider families, and other members of their networks who make up the constantly shifting assemblages within which they intra-act and affect one another, enabling them to live life to the fullest. More information on the project – including the specificities of methodology and method – can be found at the project website.<sup>3</sup>

Because our study is in its infancy we are starting to collect our empirical data. However, we know that researchers never enter a project value-free or theoretically and conceptually under-developed. In contrast, we hold the firm conviction that researchers should always be mindful of the kinds of theoretical understandings that they hold and the potential ways in which these theories might conceptualise their subject matter. Our commitment to working collaboratively with young people with LL/LTIs extends to our choice of theory. We seek theory that connects with the lifeworld of these young people. More generally, we will explore how the theoretical lexicons of affect and disability can be plundered in order to help us understand disability in the world.

#### **4. Feeling disability**

Disability can and should be an entry point into studies of affect. We might want to think about the ways in which affect economies draw disabled people and those close to them into particular ways of feeling and emoting. Like Ahmed (2004) and Pedwell and Whitehead (2012) we are wary of those affect theorists who claim that their work constitutes a brand-new field on inquiry in relation to emotion and feeling. Just as feminism can claim a long historical alignment with affect through ‘the personal is political’, so critical disability studies can also point to a body of literature that has been engaged with the affective experiences of disability (Goodley 2016). Critical disability studies is a nascent field of scholarship and activism that explicitly engages with transformative fields of inquiry including queer, postcolonial, indigenous and feminist studies. Theories of affect sit at the intersections of these different spaces of theorisation. In the following, we make some novel connections of theoretical orientations and trajectories from affect theory and critical disability studies.

##### **4.1. *Ontological invalidation in neoliberal-able times***

How come you are in a wheelchair?

What happened to you then?

I never think of you as disabled?

You are so brave, you know. (Common comments and questions made by non-disabled people to disabled people; see Goodley 2016). It must be so difficult for you, having a disabled child, but it's a good job it happened to you, I don't think I could cope. (Personal comment made to one of the authors, no date)

A lot of people [friends] will ask, 'Does Shaun's willy work?' (Hannah, non-disabled wife of Shaun, a man with Spinal Cord Injury [SCI]; see Liddiard 2017)

The British feminist disability scholars Thomas (1999, 2001, 2002, 2007) and Reeve (2002, 2004, 2005, 2006, 2007, 2008) have created a theoretical space for thinking creatively about the psyche. As Goodley (2016) argues, both are sceptical about psychologisation but share an interest in what Reeve describes as the 'barriers in here' that are often ignored by radical structuralist sociologists who are more focused on the 'barriers out there' (2008, 1). The psycho-emotional register is progressive because it seeks to consider what 'disabled people can be' rather than what 'disabled people can do'. But this approach is also sensitised to an exploration of indirect and direct forms of psycho-emotional disablism.<sup>4</sup> Direct forms can be found in discriminatory interactions, acts of invalidation, patronising responses of others and hate crimes such as the destruction of group symbols and hate literature (Sherry 2000). Indirect forms of psycho-emotional disablism are less overt but just as damaging. They may emerge as side effects of structural disablism (a feeling of dislocation in a building that is largely inaccessible) or unintended actions, words or deeds (such as stares of curious others, patronising attitudes, need-freak requests for assistance) (see Liddiard 2014).

How are disabled people, their partners, families and allies meant to respond emotionally to these questions? By accommodating non-disabled people, perhaps offering a smile, a short answer and a response that will not make the non-disabled person even more uncomfortable. Anger, violence or rejection on the part of the disabled person would no doubt be understood by the non-disabled inquisitor as a rude emotional response of someone with a 'chip on their shoulder'. Ironically, it would at the same time serve to embody the stale ableist trope of the angry, bitter crip. Liddiard (2014, 124) recognises both the complex management of feeling and the relational politics inherent to responding in the right ways as forms of skilled emotional labour, as disabled people come to take on the diverse roles of teacher, negotiator, manager, mediator, performer and educator' in negotiating their reactions and responses – enacting forms of skilled inter-personal labour desired by the very western labour markets from which they are largely excluded (see Exley and Letherby 2001). Hochschild (1983) is clear: there are appropriate affects to display in these moments of interaction. Families with disabled children and disabled children themselves have described the affective labour that they are forced to engage with to manage the emotions of others (Runswick-Cole 2013). Disabled people have articulated the emotional work and labour required within their loving and sexual relationships with close others, showing that such labour can reach the most intimate spaces of life and self (Liddiard 2014).

In our respective work, each of us has previously drawn on Hochschild's work to explain the ways in which disabled people engage in disabling forms of emotional labour (Goodley 2016; Liddiard 2014; Runswick-Cole 2010, 2013); as disabled people, their partners and their families find themselves caught up in interactions with non-disabled people that are governed by a number of well-known social scripts (Goodley 2016; Runswick-Cole 2013). These scripts invite non-disabled people to interact with disability that permits, for example, the asking of inappropriate, demeaning and highly personalised questions and commentaries we outlined at the start of this section.

Affect is deeply embedded in cultural norms. Hughes (2009, 2012, 2015) points out that disabled people are associated with a cultural history of disgust, pity and fear. This renders disabled people as objects of ambivalent feelings from wider non-disabled society such as resentment and hatred. Disabled people risk being ontologically invalidated by the disabling worlds that they inhabit. Hughes (2009, 408) argues that:

The role of fear ... is hugely underplayed in personal tragedy theory. So too is the role of disgust, a mediating emotion in the relations between disabled and nondisabled people that is in need of considerable development.

Hughes' work builds sociologically on the psychological and psychoanalytic analysis of Marks (1999a, 1999b, 2002) that sought to probe unconscious responses to disability. Marks powerfully argued that being subjected to the damaging pathologising projections of others risked being internalised by disabled people:

where the projections of societal norms of dependency and bodily imperfection are internalised, only to sit ambivalently, often shamefully, with one's psychical position in a disabling world. (Marks 1999a; 21)

Such feelings of emotional and ontological invalidation risk self-harm and self-hatred (Marks 1999b, 615, also see Hughes 2009). Goodley too has deployed social psychoanalytic concepts to explain further the generation of fear, disgust but also attraction in relation to disability displayed by non-disabled culture (Goodley 2011, 2014, 2016). This analysis was indebted to the writings of Marks (1999a, 1999b, 2002) and Watermeyer (2013) who as therapists trained in the psychoanalytic tradition are far more skilled in deploying this theoretical language. Both were keen to understand the ontological damage done to disabled people whilst living in a society that veers from not recognising disabled people as valued members of society to conceptualising disability solely in terms of deficit and lack. Marks and Watermeyer are keen to take seriously the emotional lives of disabled people and do so with a keen interest in the socio-cultural conditions in which one's psycho-emotional life thrives or fails.

Clearly, living in such a dismissive atmosphere risks causing feelings of invalidation. Also, we know that a precarious sense of self becomes heightened in times of austerity (Flynn 2017). Goodley's (2011, 2016) interest in deploying psychoanalysis was less with disabled people and more with non-disabled people. In particular, he

played around with the idea of the psychopathology of the normals, which considers the ways in which the precarious nature of living with being non-disabled (or able-bodied or able-minded) inevitably plunges individuals into emotional turmoil (Goodley 2014). One easy route out of any psychic trouble is projection: finding failings in others. We therefore might understand feelings of disgust or fear (or attraction for that matter) as symptoms of the underlying neurosis on the part of non-disabled people. Hence, disability becomes disavowed by normative culture: it is rejected (because it symbolises lack) and adored (because of its association with dependency which is the human condition desired by most of us caught in the terrors of adult autonomy). While some affect theorists consider the field to be in part a rejection of the psychoanalytic ownership of the affective register, psychoanalysis may be critically reappropriated to make sense of wider cultural formations of emotion. Indeed, Gorton (2008) and Duschinsky, Greco, and Solomon (2014) draw on related concepts of attachment and fantasy in their interrogation of affective culture. Duschinsky, Greco, and Solomon (2014, 232) note that the idea of attachment might well be the best way to engage with a vital question left behind by Foucault: why we emotionally invest in the cultures and institutions which discipline our identities and limit our potential to flourish. For Duschinsky, Greco, and Solomon (2014) this is the root of Berlant's affective notion of cruel optimism: 'an optimistic attachment is cruel when the object/scene of desire is itself an obstacle to fulfilling the very wants that bring people to it: but its life-organising status can trump interfering with the damage it provokes' (Berlant 2011, 227). The consequence of such cruel optimism risks causing emotional distress, as one fails to match up to the labour and consumption demands of late capitalism. One route out of such distress is to unconsciously view and locate failure in others. This might help us explain the cultural disavowal of young people with LL/LTIs and their families.

We might understand the broader cultural politics of emotion or affect economy (Ahmed 2004) – against which interactions such as those already described take place – as one being framed by ableism (Campbell 2009; Goodley 2014). Ableism is associated with the broader cultural logics of autonomy, self-sufficiency and independence. These logics are unquestionably and uncritically linked to psychological contentment and the affect of happiness. Ahmed ([2007] 2008) urges us to shake up our taken-for-granted ideas around happiness. Indeed, her critique of the pursuit of happiness, which is promulgated by psychological therapies and the self-help industry, fits well with a critical disability studies rejection of neoliberal-ableism. The latter discourse similarly propels the individual citizen towards an end of point of supposed contentment through the never-ending performances of labour and consumption. Happiness is to be bought, and so is able-bodied and able-mindedness. Here we can see further connections with Berlant's (2007, 2010, 2011) cruel optimism: the mistaken desire and belief that we will reach personal fulfilment and happiness through working and shopping hard enough. Happiness, for Ahmed ([2007] 2008), can be understood as a promise or aspiration, a habit, a

narrative, a memory, as well as an emotion, feeling or affect.<sup>5</sup> We would want to consider ability (and the desire of autonomy tied up within ableism) in similar ways. Neoliberal-ableism is the elision of individual and national economic independence with an individual and cultural celebration of autonomy (Goodley 2014). This particular cultural economy ties individual and national progress to independence and, by virtue of this, associates happiness with self-sufficiency. Young people with LL/LTIs risk being threatened with what Flynn (2017, 155) describes as a 'lived experience of shock and disappointment' that can further devalue their identities as young disabled people. We would want to understand and contest the affective consequences of neoliberal-ableism.

#### 4.2. *Affect aliens and crip killjoys*

About 4 years ago we submitted a research project application to work with young disabled people with life limiting impairments. Eventually we got back the reviewers' comments. Of the six, four were glowing, one lukewarm and the final one dismissive. Project funding was rejected. Our most critical reviewer wrote 'While I accept the research team want to work with disabled young people, the focus on life-threatening impairments runs the risk of re-energising the personal tragedy model of disability: a perspective that disabled people and their organisations have been trying to distance themselves from for a number of years'. (Personal anecdote, name withheld)

So far, our discussion has outlined a rather top-down affair in relation to the cultural reproduction of affect. Ahmed (2010) offers a more resistant politic. Ahmed has happiness as her target when she writes that 'the feminist killjoy spoils the happiness of others; she is a spoilsport because she refuses to convene, to assemble, or to meet up over happiness'. She is interested in critiquing happiness as the affect reproduced by a capitalist society:

Does the feminist kill other people's joy by pointing out moments of sexism? Or does she expose the bad feelings that get hidden, displaced, or negated under public signs of joy? Does bad feeling enter the room when somebody expresses anger about things? Or does the entry of anger simply mean that the bad feelings that circulate through objects get brought to the surface in a certain way? The feminist subject in the room hence brings others down, not only by talking about unhappy topics such as sexism but by exposing how happiness is sustained, by erasing the signs of not getting along. Feminists do kill joy in a certain sense: they disturb the very fantasy that happiness can be found in certain places. To kill a fantasy can still kill a feeling. It is not just that feminists might not be happily affected by the objects that are supposed to cause happiness but that the failure to be happy is read as sabotaging the happiness of others. Feminists might be strangers at the table of happiness. (Ahmed 2010, 582)

She goes on:

I want to think of consciousness of the *un* in *unhappy* as consciousness of being not. Consciousness of being *not* or *un* can be consciousness of being already estranged from happiness, of lacking the qualities or attributes required for a happy state of existence. To be not happy is to be not in the eyes of others, in the world of whiteness, which is the world as it coheres around right bodies, or the white bodies. Consciousness of being not

involves self-consciousness; you recognize yourself as the stranger. (Ahmed 2010, 589; original emphases)

We can draw parallels with crip politics here. Johnson and McRuer (2014) and Tsakiri (2016) extend the idea of the crip killjoy who resists imposed positionings by normative society. Disabled people are similarly strangers at the neoliberal-able table that only recognises self-sufficiency. To Ahmed's 'un' and 'not' we can add 'dis'. To be or become disabled is to work against a normative ableist culture that pursues its own happiness through a celebration of individuated autonomy. 'There is solidarity in recognizing our alienation from happiness', Ahmed (2010, 592) argues, 'even if we do not inhabit the same place (and we do not). There can be joy in killing joy. And kill joy we must, and we do'. We might think of rephrasing this affective politics thus: 'there can be joy in dissing ability. And dis ability we must, and we do'. We might view young people with LL/LTIs as unintentionally occupying the position of crip killjoys because their shortened lives and limited or life-threatening impairments sit in stark contrast to the ableist ideals of contemporary life. Indeed, even in the potentially more liberating contexts of the disabled people's movement, normative ideas about valued lives have been articulated. The 'Not Dead Yet' slogan from the United States seeks to distinguish between the pride one has in a disabled life contrasted with the finality and tragedy of death. Young people with LL/LTIs subvert this affective logic. They appear as what we might term affect aliens: alienated by the ableist logics of living a standard life and, importantly, alienating others by their presence. The shame associated with this disability–life–death complex rears itself not in young people with LL/LTIs but in relation to those (disabled) people who unknowingly maintain a dangerous simplistic distinction between a standardised split of life and death.

### **4.3. Disability and resistant assemblages**

At a recent university event showcasing robotics and human enhancement research, a group of young disabled people who are also users of Alternative and Augmentative Communication (AAC) were preparing for their presentation. During conversations with the organising team of the university, one of the young people explained that she worked closely with her family, personal assistants and technology professionals to ensure that the AAC provided bespoke language and favoured sayings. Using the hardware to tell her older brother to 'fuck off' was a key element of these discussions. (Dan Goodley, personal anecdote, November 2014, somewhere in the United Kingdom)

Braidotti's (2005, no page) brand of affect theory is associated with a 'nomadic affectivity'; an outwardbound perspective based on complex relations with a multiplicity of others, 'including nonhuman others'. This perspective seeks to understand affect, body and the environment as intimately connected and materialised phenomena; raising questions about how we might relate to one another in different ways. According to Feely (2016, 868), Braidotti's work has been crucial to the 'ontological turn' within continental philosophy which has brought forth 'the

emergence of new ontologies and methodologies, which seek to explore both the material and semiotic forces which make up reality, without a return to essentialism'. This ontological turn has invited in new materialist analyses, thus offering us a way out of the critical realist versus poststructuralism debate that plagues critical disability studies. Critical realists such as Shakespeare (2014) and Vehmas and Watson (2014) lambast poststructuralist leanings within critical disability studies for ignoring the stark realities of impairment. However, for Feely (2016), the self-defined 'critical realism' of these scholars actually lacks criticality because it imports simplistic essentialist ideas of impairment and the body. These interventions, he suggests, lack a more nuanced and dynamic engagement with the materiality of life. For Feely (2016) such an engagement is offered through bringing in the work of Deleuze and Guattari (for example, Deleuze and Guattari 1987) and to this we would add Deleuzian scholars, in particular the work of Braidotti (for example, Braidotti 2003, 2013). In Feely's (2016) beautifully accessible piece he notes that for Deleuze reality is made up of discursive statements and material entities. Both are active, mutually affecting and have effects in the world (Feely 2016, 869). Deleuze's materialism, indebted to Spinoza:

allows us to think and speak about bodies (or any entities). However, it insists that we reject the traditional preoccupation with essentialist questions ('What is a body?') and focus instead on its currently actualised, or what Deleuze calls actual, capacities ('What can a body do?') as well as its potential, or what Deleuze terms virtual, capacities ('What else could a body do?'). (Feely 2016, 870)

A body's capacities – the things it can and cannot do – are always contextual and relational (think technology, material resources, communities of support). Within Deleuzian terminology, when a body is ascribed one of these identities (e.g. 'a person with a profound intellectual disability'), it is 'over-coded' and this prevents us from thinking creatively about the infinite number of things this body can or could do in different contexts (Feely 2016, 872). Embodied affects (e.g. joy) and visceral sensations (e.g. pain) can profoundly affect the discursive thoughts a body has and the words it speaks. At the same time, discursive thoughts or statements can trigger embodied affects and emotions.

Hence, for Feely (2016) the body is a ceaselessly becoming-body in a dynamic relationship with the environment. In order to understand the complex relationships we need to turn outwards to consider the relation of the body with other embodied and non-embodied entities. We need to explore assemblages.

Attending to the extension of the disabled body through connections with other humans and non-humans produces a number of affective realisations. Let us pick out three (see Goodley, Lawthom, and Runswick-Cole [2014] for elaboration). First, disability is affirmed as the subjective and embodied position that reaches out for connection with others. Disability is necessarily affective: it has the potential to affect and be affected (Fox and Alldred (2015)). Second, the human subject is exploded, shifting us from a preoccupation with the original humanistic fixed subject position (disabled person) to a recognition of the distributed machinic

assemblage of humans and non-humans (a posthuman complex). The affective moment is found in the complex merging of wet and hardware and human relationships. Third, disability is both centralised and decentralised. Disability is centred when it calls for assemblages and connections with others. Disability demands interdependency. As the assemblage grows, so disability loses its importance: it becomes decentred. The flows of connections and networks erase the original disability subject and replace it with a complex rhizomatic web of relationships. The AAC user is both a proud disabled person and a merging of organic and inorganic matter: a posthuman subject. The bodies and selves of young people with LL/LTIs are maintained through their complex integration in and through multiple technologies, caring practices and intimate labours (intimate assemblages), medical intervention and knowledges.

## 5. Conclusions

In this article, we have introduced a number of theoretical developments of affect theory. We have considered the extent to which some of these concepts might connect with disability; specifically through considering the lives of young people with LL/LTIs and their families. While our research project is in its infancy, our analysis suggests that young people so labelled are subjected to a whole host of emotional responses that say more about the precarious affective state of dominant culture. Critical disability studies must challenge cultural norms that risk further pathologising disabled people. The affective register is always a cultural and embodied register and it is here we might find moments of resistance as young people connect with others to contest normative ideas that assume their incompetence and emotional immaturity. New affective relationalities are made possible through disability's hybridisation of human and non-humans.

These dalliances with feeling disability raise some significant questions about the future direction of critical disability studies. We have chosen three to conclude this article. First, we wonder whether there is a place for the humanist human in theorising when affect studies trouble individualised and interiorised versions of emotion. Do we want to have any relationship with traditional sciences of the individual such as psychology and psychoanalysis when these very sciences have contributed, in part, to the pathologisation of disability? What becomes of human rights if we give up on humanism? Second, should disability studies have any interest in subjectivity especially when the personhoods of disabled people have been historically marginalised? Our review of affect theory finds subjectivity to be understood as an old-fashioned term but we recognise that it holds theoretical purchase in critical disability studies especially when thinking through the emotional impacts of oppression. For this reason we are loathe to discard it. Third, how might disability be pushed into the foreground of contemplations about the contemporary reproduction of affect? For example, when new materialist theories distribute affect across assembled relationships of humans and non-humans then they have

the potential to connect disability studies with Science and Technology Studies. Too often, however, disability is configured as an object or product of science and technology rather than the starting subject for debate (Goodley, Lawthom, and Runswick-Cole 2014). Our ambition would be for disability to provoke analysis of human affect in a time of turbulent economic, technological and political change.

## Notes

1. For examples of these Christmas television adverts, see 2016, Accessed June 1, 2017. [https://www.youtube.com/watch?v=sr6lr\\_VRsEo](https://www.youtube.com/watch?v=sr6lr_VRsEo); 2015, <https://www.theguardian.com/media/video/2015/nov/06/john-lewis-debuts-2015-christmas-advert-manonthemoon-video>; 2014, <https://www.theguardian.com/business/video/2014/nov/06/monty-penguin-john-lewis-christmas-advert-video>; and 2013, <https://www.youtube.com/watch?v=NW2EmATcb6o>.
2. See [www.shef.ac.uk/ihuman](http://www.shef.ac.uk/ihuman).
3. See Accessed June 1, 2017. <https://livinglifetothe fullest.org/>.
4. A point developed by Reeve and also by Carol Thomas (2007, 72).
5. 'Some things become good, or acquire their value as goods, insofar as they point toward happiness. They become happiness pointers, as if to follow their point would be to find happiness ... Happiness does not reside in objects; it is promised through proximity to certain objects. The promise of happiness takes this form: if you do this or if you have that, then happiness is what follows' (Ahmed 2010, 576).

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