Dis/Entangling Disability, Mental Health, and the Cultural Politics of Care

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ABSTRACT

This paper explores how understandings of care can be prefigured through engagements *with* concepts of ableism and sanism as productive and radical companions for (re) thinking care. Working with family carers and people with learning disabilities as part of a co-produced project based in England: *Tired of spinning plates: an exploration of the mental health experiences of adults and/or older carers of adults with learning disabilities* (National Institute for Health and Care Research (NIHR) 135080, October 2022-November 2024), we notice the absence of the concepts of ableism and sanism in theorisations of the cultural politics of care. We begin by describing family carers' complex entanglements with categories of 'carer', 'learning disability', and 'mental health'. We draw on theorisations of ableism and sanism to inform our analysis of caring relationships, attending to the dis/temporalities and dis/locations of care and the centrality of dis/political love. We conclude by reflecting on what academics, policy makers and practitioners might learn about caring practices from family carers and people with learning disabilities, crucially acknowledging and embracing the power of dis/political love in caring relationships.

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INTRODUCTION

In (post)pandemic times, there has been a proliferation of debates about the changing nature of care (Mahajan et al. 2020). Discussions of care matter because, despite the ubiquity and mundanity of the term, the meaning of care has often been ill-considered or taken-for-granted, leaving the dominant narratives that construct people's lives untroubled (Drotbohm 2022). We welcome recent scholarship that has sought to (re)engage with care and to consider Black Feminisms, Indigenous and Decolonial Feminisms and Social Reproduction Theory (Woodly et al. 2021). This includes disability justice, the political, intellectual, and artistic movement founded and led by Black, Indigenous, other people of colour, queer and disabled activists over the past two decades who are collectivising care in radical ways in disability communities and 'visioning a world where we flourish, that values and celebrates us in all our myriad beauty' (Piepzna-Samarasinha 2018: 21). We want to learn from these attempts to unsettle dominant narratives of care by paying attention both to its messiness and to its radical potential for transformation (ibid.). We want to engage in a dialogue with those who seek to preconfigure care as an 'irresistible impulse to justice' (McLeod 2019: 267). And yet, as we begin to engage with these discussions, we notice the marginality of theories of ableism and of sanism in these (re)theorisations (Goodley 2014; Perlin 1992).

Our aim here is to create a space to think again about how a cultural politics of care might be prefigured through an engagement *with* critiques of ableism and sanism as potentially productive and radical concepts for thinking with people with learning disabilities and their carers. We are not only interested in what 'care' *is*, but what care *does* and what it *makes im/possible* in people's lives (Ahmed 2014). We do not align with a singular theory or account of care but consider how care moves between bodies, paying attention to relational, affective and practical flows. We understand care as being inextricably interwoven with politics, emotion and embodied feelings and include these as important aspects of contemporary cultural and political thinking (Goodley et al. 2018). We want to disrupt the stagnant assumptions of care as something mundane and every day and to invite, instead, an ongoing critical engagement with more uncomfortable conceptualisations of care which are gendered, racialised, and, crucially for us, written through with ableist and sanist assumptions.

We have become entangled with these critical engagements as part of a research project based in England: *Tired of spinning plates: an exploration of the mental health experiences of adults and/or older carers of adults with learning disabilities* (National Institute for Health and Care Research (NIHR) 135080, October 2022–November 2024). In this participatory, arts-informed project, we are working with family carers and adults with learning disabilities to understand their experiences of care, mental health, and support.

We write from the context of the UK where, pre-pandemic, there were approximately 9 million carers (Carers UK 2020). Despite policy drives to support people with learning disabilities to live independent lives, in England in 2021/22, 36% of adults with learning disabilities aged 18–64 in receipt of long-term social care (47,835 people) were living with their families. There are no figures for people over 65 (Digital National Health Service (NHS) 2022). A sustained period of austerity in the UK has led to cuts to services and support available to carers of adults with learning disabilities (Forrester-Jones 2021). This has been worsened by the far-reaching negative impacts of the COVID-19 pandemic (Patel et al. 2021; Hatton et al. 2024).

It is in this context that we find ourselves in a position of trying to pull together and apart the ways in which care, disability, and mental distress are entangled with one another in people's lives, research and public policy discourse. We recognise this is important if we are to challenge dominant beliefs and normative constructions and practices of care that have the potential to construct and sustain inequality in inter/national neoliberal contexts. Indeed, we believe that a pedagogy of discomfort (Foucault 1994) helps to uncover and question deeply embedded assumptions about care that silently construct day-to-day lives. We agree that discomfort offers the transformative potential to trouble deeply held assumptions about care, mental health, and disability (Zembylas 2005). Most of the authors of this paper are all mothers of children or adults with learning disabilities. This means that we are deeply entangled with matters of care in the lives of people with learning disabilities and that our experiences drive the focus of our inquiry. We know that when we provoke discomfort, we also run the risk of being cast in the role of 'feminist killjoys' who, by naming the problem, become the problem

(Ahmed 2017). Nevertheless, our aim is to make a positive contribution to these debates about care as an attempt to move towards a more collective and expansive cultural politics of care which also attends to the workings of ableism and sanism. Crucially, we do so in solidarity with carers and with adults with learning disabilities.

We consider it imperative to highlight here that 'learning disability', 'carer', and 'mental health' are contested terms and throughout this paper, and elsewhere, we critically trouble the terminology we use (Smith et al. under review). The troubles are revealed by both the literature and through our discussions with family carers involved in the project public involvement group, the Tea and Cake Group, and exposes a persistent disidentification with the term 'carer' by family carers (Lloyd 2006; Guest and Corrigan 2018). On-going critical engagement with these troubles also continues in relation to the terminology used to describe people with 'learning disabilities' (Goodley and Rapley 2001; Cluley 2018). Some people described as 'mentally ill' or as having 'mental health issues' have also begun to disidentify with these terms, preferring 'mental health service user' (Beresford and Russo 2016). Throughout, we remain sensitive to the ongoing ontological assumptions and repercussions of the words we use (Smith et al. under review).

DISABILITY AND ABLEISM

We begin our work writing from a critical disability studies perspective (Goodley 2014). We understand disability as a phenomenon that has long been associated with discrimination against people with physical, sensory, and cognitive impairments (Oliver 1990; Oliver and Barnes 2012). We recognise this discrimination is often also extended to those closest to disabled people, including family members, friends, and other allies – a form of discrimination identified by the sociologist Erving Goffman as 'courtesy stigma' (Goffman 1963) and we include people with learning disabilities and their carers in considerations of disability justice (Ryan and Runswick-Cole 2008).

Crucial to our scholarship is a rejection of the often taken-for-granted perception of disability as an individual flaw or lack; we embrace disability as an opportunity to challenge exclusion and marginalisation and with the potential to unsettle the current order (Goodley et al. 2019). Critical disability studies are concerned with the ways in which ability and disability are produced in relationship with one another – not as 'things', often conceived of as binary opposites, to be celebrated or disavowed (Hall 2019). We recognise the ways in which ability and dis/ability are co-constitutive of each other (Goodley 2014). Disability studies scholarship has a long tradition of interrogating disablism, which is usually understood 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.' (Thomas 2007: 73).

Undoubtedly, a key contribution of disability studies to critical scholarship has been an increasing orientation towards exposing and challenging ableism which casts disability as a diminished state of being human (Goodley 2014). Ableism is described by Campbell, 2009: 5 as:

> 'a set of beliefs, processes and practices that produce – based on abilities one exhibits or values – a particular understanding of oneself, one's body and one's relationship with others of humanity, other species and the environment, and includes how one is judged by others. Ableism reflects the sentiment of certain social groups and social structures that value and promote certain abilities, for example, productivity and competitiveness, over others, such as empathy, compassion and kindness.'

Ableism is produced in cultures where disability appears as unexpected, often unwelcome, and unhelpfully disruptive to normative expectations and desires. Ableism, understood as antipathy towards disability, is inevitably tangled up with disablism, understood as discrimination against disabled people (Thomas 2007).

To theorise ableism is always to critique and unsettle dominant narratives (Goodley 2014). Hall (2019) describes the ways in which theories of ableism have been used to interrogate: what disability is (Carlson 2001); how ableism works with and is entangled in the production of race (Campbell 2009); troubling the concept of resilience (Hutcheon & Wolbring 2013), and sexuality (Baril & Trevenen 2014). Our aim here is to begin to interrogate care through theories of ableism and sanism, as we describe below.

MENTAL DISTRESS, MAD STUDIES, AND SANISM

There is a close and sometimes complicated relationship between critical disability studies and Mad Studies (Morgan 2021). Mad Studies is an evolving interdisciplinary field which seeks to disrupt, counter, and unsettle dominant discourses on mental health (Castrodale 2017). Mad Studies foregrounds the experiences and knowledge of mental health service users/ survivors with an emphasis on generating new knowledge, approaches and actions that value the experiences of Mad-identified people (Daley, Costa and Beresford 2019). A Mad Studies approach also affords opportunities to reclaim the term 'mad' and to challenge its negative connotations with more positive understandings (Rashed 2019). Mad Studies scholarship has critiqued dominant global North models of mental health which have generally framed human response to mental distress and difficulty in medicalised and individualistic terms, locating the 'problem' or 'pathology' firmly within the individual (Beresford and Rose 2023).

Critical disability studies and Mad Studies-informed approaches share a commitment to troubling biomedical accounts of disability and of mental distress, criticising the dominance of the knowledge and practises of the psy-disciplines (Rose 1998). While critical disability studies aligned approaches often draw on the concept of ableism (Goodley 2014), Mad Studies invokes sanism as a way of describing the persistent fear, victimisation, and brutalisation of those considered to be 'mentally ill' (Perlin 1992: 45). While ableism is becoming widely employed in academic literature (Goodley 2014), sanism is less well known and utilised. Sanism describes the pervasive and systematic subjugation experienced by people who have experienced 'treatment' for their mental health and/or attracted mental health diagnoses (Poole et al. 2012). Poole et al. (2012) explain that sanism, like racism, sexism, and ableism, can result in direct discrimination, but that it is often felt at the level of 'microaggressions', every day, subtle insults, which culminate in both 'internalised stigma', which results in people being fearful of seeking support, and 'public stigma' where the wider public and professionals agree, overtly or tacitly, with negative stereotypes of people who experience mental distress. Sanist myths dominate social discourse and practice so that 'mentally ill' people are constructed as 'different' and 'less than' other people; they are 'dangerous and frightening' and 'incompetent' (Perlin 1992: 45–46).

While we recognise that Mad Studies seeks to foster a 'unique' contribution distinct from critical disability studies (Beresford and Russo 2016), we suggest that sanism and ableism are closely intertwined in the lives of people with learning disabilities and their carers, and that they have both often been marginalised in theorisations of care. At the same time, there has been limited engagement with the lives of people with learning disabilities and with their carers in the field of Mad Studies (Mills and LeFrancois 2018).

THE CULTURAL POLITICS OF CARE

In 1990, Fisher and Tronto (1990: 40) defined care as:

> '[a] species activity that includes everything that we do to maintain, continue and repair our world so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web'.

Tronto's work has been widely recognised for calling our attention to the racialised and gendered inequalities perpetuated by care, nourished by neoliberal market logics (Woodly et al. 2021). In 1990, Fisher and Tronto offered an analysis which distinguished between different phases of care: caring about; caring for; caregiving and care receiving. In their discussion, 'caring about' is constructed as being determined by what or who we know but little in the way of skills and resources is required to care about someone or something. This is juxtaposed with the conceptualisation of 'caring for' which is described as requiring the carer to have the skill and resources to take responsibility for the recipient of care. Meanwhile, 'caregiving' is presented as a 'heavier responsibility' and the hands-on work of 'maintaining and repairing our world' (Fisher and Tronto 1990: 43). Fisher and Tronto differentiate 'caregiving' from 'taking care of' by characterising it as a 'more continuous and dense time commitments than taking care of' (ibid.). Care receiving is understood as involving 'the response of the thing, person or group that received the caregiving' (Tronto 1998: 17).

And yet, as we approach Tronto's seminal feminist scholarship, we note the absence of ableism and sanism from the analysis. While Tronto (1993) pays attention to the constitution of care through sexism, racism, colonialism, capitalism, imperialism, and cisheteropatriarchy, disablism and sanism are missing from the analysis. In popular culture, policy documents and in (folk) psychology, disabled people and people who experience mental distress are usually imagined as the recipients of care or as a potential threat to their carers' mental wellbeing (Hughes et al. 2005).

We are not the first to draw disability and mental distress into discussions of the cultural politics of care. We know that others share our discomfort when disability is repeatedly cast as a 'problem' which carers suffer as a 'burden' they are required to carry (Herring 2014). Research underpinned by biomedical and individualised models of mental health and of disability has long theorised practices of care as a threat to mental health and well-being (Lazarus and Folkman 1984). Sustained periods of care are said to increase anxiety and depression and cause 'burnout syndrome … the emotional manifestation of the stress experienced by carers' (Lindgren 1990). Despite the contested status of the term 'burnout,' it is used extensively in research, and in everyday life, in discussions about carers' mental health locating the 'problem' of care in the individual experience of carers and in the assumed 'deficits and lack' of those they care for – rather than wider social injustice (Heinemann and Heinemann 2017). The literature which focuses on the lives of carers of adults with learning disabilities is often saturated with problematic assumptions about difference as "Other" in relation to the categories of 'learning disability', 'mental health' and 'carer' (Smith et al. under review).

While in its everyday use care is usually constructed as benign and kind, historically, disabled people and people who experience mental distress have, in the name of care, been subjected to forced sterilisation, painful rehabilitative therapies, physical and emotional abuse, and institutionalisation (Kelly 2011). In contemporary times, abuse in the name of 'care' persists globally and in the United Kingdom. The Joint Committee on Human Rights (UNHCR, 2016), for example, reported that people with learning disabilities and/or autism experience widespread systemic neglect and abuse delivered by 'carers' in 'caring' and 'therapeutic settings' (Davies and Plomin 2019).

Issues of dependency, interdependency, and autonomy between carer and the person cared for have been central to the debates with feminist and disability literatures approaching these issues from different perspectives. Feminist scholarship emphasises the role of the (imagined to be sane and non-disabled) caregiver, while disability studies scholarship centres the recipient of care (Hughes et al. 2005). Hughes et al. (2005) call for feminists and disability scholars to make common cause and recognise the need, emotion, and embodiment of caregiving while recognising the citizenship of the care recipient. Pettersen (2012: 376) draws on Gilligan's (1982) concept of 'mature care' to argue that concepts of care must be built around the 'equal worth of the carer and the cared for'. While Kittay (2019) takes care to remind us of the 'nested dependencies' of power in relation to care relationships. She argues that we must also pay attention to the conditions in which care is provided; the influence of the welfare state on the care provided by the private sector, civil society, and the family. Care is always relational.

In a rapid scoping review of literature concerned with the mental health of family carers, Smith et al. (under review) also found that the context of the family produced a willingness of family carers to share experiences, offering support to others. The authors invoke a 'commoning for care' as a way of expressing the power and collectivity of carer-carer support. However, no papers in the review primarily focused upon positive aspects of caring. Threads of love, friendship, and humanity were woven through the literature, but 'love' too often appears as an unexpected and intrusive presence in literature otherwise saturated with ableist and sanist assumptions (Smith 2021). And yet despite the absence of love in the literature which examines the mental health of carers of people with learning disabilities and their families, Smith (2021) writes about care in the lives of parents and disabled children, and centres love in her analysis. For Smith, love has escaped its sentimental and private moorings to matter in public lives.

> 'This is not a maternal forgive-all love phenomena but a love-at-work that is fearsome, fearful, intrudes and demands response-ability (Barad, 2007).' (Smith 2021: 122).

This fierce love is 'dis/political love' provoked by the neoliberal-developmental- ableist contexts in which parents raise disabled children providing 'a site for collective becoming' (Zembylas 2017: 26 cited in Smith 2021: 118).

(CRIPPING) TIME-SPACE AND CARE

Theorisations of the conditions of care have been widely influenced by growing literature focused on the geographies of care. Milligan and Wiles (2010), describe a need to focus the 'landscapes of care' centralising both location and temporalities, arguing that analysis of landscapes of care must include exploration of 'past experiences and future expectations; the various temporal rhythms and routines of care' (Milligan and Wiles 2010: 740). Building on this work, Bowlby (2012) describes caring scapes as a way of paying attention to the multidimensional nature of care, thinking about current and future caring across the life course. We welcome an approach that pays attention to the location(s) and temporalities of care but are wary of appeals to life course theory which assumes a unilinear model of staged progression from birth to death that moves from dependency (childhood) to independence (adulthood) and dependency again (older adulthood) (Ljuslinder et al. 2020). This developmental model places the indeterminate and uniquely experienced temporalities lived by disabled people and their carers as out of step and out of (unilinear ableist) time (Smith 2021). Disability scholars seek to disrupt pervasive notions of linear and progressive time with its normative assumption of stages of life (Samuels 2017) through the embracing of 'crip time' as an analytical tool for recognising and celebrating the indeterminate temporalities of diverse lives (Ljuslinder et al. 2020). We need to pay attention to the locations and temporalities of care *and* the workings of ableism and sanism, in order to (re)territorialise the landscapes of care by embracing their dis/locations and dis/temporalities.

LOCATING THE STUDY

We explore the mental health experiences of carers of adults with learning disabilities through an on-going research project based in England: *Tired of spinning plates: an exploration of the mental health experiences of adults and/or older carers of adults with learning disabilities* (NIHR135080, October 2022–November 2024).

Our project aims to: (1) centralise the principles of co-production to ensure that carers are research leaders; (2) take an innovative participatory approach using a digital storytelling methodology that captures the stories of carers and their mental health experiences; (3) design a public engagement and dissemination strategy that raises wider awareness of the mental health of carers of adults with learning disabilities; and (4) develop learning and teaching resources that support carers and inform the development and delivery of high-quality mental health services to meet their needs.

We are working alongside family carers and adults with learning disabilities to understand carers' experiences of mental health, services and support. Participants were recruited through the research team's professional and personal networks, including links to family carer organisations and self-advocacy groups led by people with learning disabilities. Information about the project was shared by partners' email lists and social media pages and across wider social media platforms. A public involvement group, the Tea and Cake Group, was convened at the beginning of the project to provide guidance, feedback and advice on each phase of the research and to act as participant-co-researchers. Group discussions form part of the project data as members draw upon their own experiences of care and caring as they reflect on the on-going research. A group of six carers and three adults with learning disabilities meets bi-monthly across the twenty-six-month project. These reflections are captured in a co-authored blog curated by the project's public involvement group, the Tea and Cake group, and published on the project website: https://sites.google.com/sheffield.ac.uk/tiredofspinningplates/home. The group guides us as we move through the research phases of a co-designed survey for carers, interviews, digital story making workshops and the development of learning and teaching materials for carers, people with learning disabilities and allied professionals.

We have also been working with another six family carers to co-design a survey about carers' mental health. Over a period of a month, we held two online workshops. Our original plan was to work with family carers at the workshops to develop an online survey with them about carers' mental health. During the workshops, carers spoke about their experiences of care and caring and mental health. They concluded that it would not be possible to capture their complex experiences through a 'tick box' survey and so we followed their advice to move to an online depository to which carers can submit text, pictures, artwork, videos and sounds to reflect their experiences. We report on this change in more detail elsewhere (Runswick-Cole et al. under review).

This paper is based on the analysis of the data from both the detailed notes and blogs created at the Tea and Cake group meetings and the detailed notes made by the researchers at the co-design survey meetings (see Tables 1 and 2). Traditional demographic data was not collected from these participants as we consider identities as becoming, ongoing and in flux with that which (re)produces them with every intersectional remaking of the world (Barad 2007). This includes a remaking with theory through this paper's iteration of lives and of care. This research does not seek 'population' generalisation but to invite a thinking together *with* theory and the lives entangled with this work as provocation for social justice. We remain committed to the ways in which care and caring are reproduced as concepts through each reiteration of becoming (Barad 2007; Jackson and Mazzei 2022). The work is not to centralise fixed representational labels but to centralise the ongoingness of disability, care, and human lives.

NAME	CARER/PERSON WITH LEARNING DISABILITY
Bea	Parent
Matthew	Sibling
Julie	Parent
Emma	Person with a learning disability
Elspeth	Parent
Grace	Sibling
Carrie	Parent
Devi	Person with a learning disability
Daniel	Person with a learning disability

Table 1 Tea and Cake Group Participant Table.

NAME	CARER
Deanna	Parent
Tamsin	Parent
Caitlin	Parent
Florence	Parent
Amir	Sibling

Table 2 Survey workshop participants.

We are mindful of our ethical responsibilities both to group members and to ourselves, as academics who are also carers for people with learning disabilities. We know too well the pressure carers are under. Informed consent was sought and obtained from all the participants in the study. We took time to explain the information sheet and consent forms to participants, which were available in easy read formats as well as standard text. Crucially, we saw the consent process as on-going. This means that we checked in with participants to make sure that they were happy to continue to participate during workshops and meetings, we also checked in with participants after the meetings to signpost to further support, where needed. Ethical approval for the study was obtained from *The University of Sheffield Ethics Panel*.

We designed the project so that group members can contribute in different ways, working flexibly and responsively as a supportive team. We appreciate the fluctuating demands on carers time so offer different levels and modes of involvement, from emails to phone calls, video chats, and in person meetings. Group members were remunerated for their time, and additional funds were sought for travel and subsistence and to meet access requirements, including care replacement costs. We have worked with the group to decide how the meetings will be run, planning for shared decision making, agenda setting and establishing a distress protocol for discussions of difficult topics, which includes taking a break from the discussion, signposting members to sources of support and following up with people after the meetings.

ANALYSIS

The process of analysis began even as we generated detailed notes in the Tea and Cake meetings and in the survey design workshops. After the meetings, and in line with traditional approaches to thematic analysis (Braun and Clarke 2022), we began by reading and re-reading meeting notes, thinking about the content and interconnections or disruptions between contributions and contributors. Our reading was heavily influenced by our desire to disrupt dominant narratives of care and to do so through theorisations of ableism and sanism. We were also mindful of the 'looseness' of our data which had been constructed between the three of the authors in an online word document during the meetings. We drew on Brinkman's (2014: 723) concept of the 'abductive tool-user, the bricoleur, the craftsperson' to avoid focusing on 'coding', instead thinking about the 'astonishment, mystery and breakdowns' in our collective reading and sense-making. In our discussions, we followed MacLure (2010), as we found ourselves intensifying our gaze upon fragments of the text as we searched for meaning, making connections between our readings of ableism, sanism and disability and the carers' views and experiences. MacLure (2010: 382) describes the way in which data begins to glimmer and to glow, discussing glow in terms of affect, 'resonating in the body and in the brain'. In our reading and our collective sense-making we were drawn to the moments in the discussions that 'glowed' for us, we acknowledge that this means that some participants voices are heard from more directly than others in the analysis, however, all participants were collectively engaged in generating the discussions which from which the analysis has been generated.

Only the university-based researchers were directly involved in the first stages of generating the analysis. While we understand this approach might be considered as undermining the principles of co-production, we were wary of asking too much of family carers and of people with learning disabilities. We checked in with family carers that they were happy for us to do this level of analysis (Crocker et al. 2017). We summarised our collective reading and created an easy read document to share with the Tea and Cake Group and with the family carers who took part in the survey co-design workshops (available as a supplementary document). The feedback and commentary received in response to these Easy Read documents are included throughout the analysis where applicable.

Below we share our readings and sense-making as we attempt to capture people's entanglements with theories and practices of 'care', 'learning disability' and 'mental health' and have potential to shape policy and practice. We explore: the dis/avowal of the categories of 'care', 'learning disability' and 'mental health'; the dis/locations and dis/temporalities of care; and dis/political love.

DIS/AVOWAL OF 'CARER'

Research identifies persistent disidentification with the term 'carer' by family carers as a barrier to seeking and accessing support services (Lloyd 2006; Guest and Corrigan 2018). Zucker (2004) describes how people disavow their social identity to avoid dealing with the reactions of other people. In psychoanalytic usage, disavowal refers to the distancing of the self in the face of trauma or taboo (Bennett et al. 2013). Zucker (2004) suggests that disavowal is more successful when the social identity is invisible or marginal as is the case for carers and for some people with learning disabilities and mental health issues. We offer a disruptive reading of disidentification with the categories of 'carer'; 'learning disability' and 'mental health' in the lives of family carers and of people with learning disabilities to think about the disidentification with social identities through the lens of ableism and sanism. We describe this process of rejection of and engagement with the identity categories as dis/avowal to re-centre ableism and sanism in the analysis.

As people introduced themselves in the Tea and Cake Group meetings and survey workshops they drew on the category of 'carer'. However, their introductions revealed some ambivalence about describing themselves as 'carers'. Grace (sibling carer) was hesitant: 'I suppose I'm a sibling carer' while Bea (parent carer) directly disidentified the term: 'I'm a parent, never a carer'. For Zucker (2004) this may appear to be an example of individuals rejecting a stigmatising social identity, but Matthew's (sibling carer) rejection of the term appeared to relate to discomfort with the binarisation of the terms 'care-giver' and 'care-receiver' (Hughes

et al. 2005) as he explained 'I don't *care* for my sister, we *exist* in the world together… *Get back to your textbooks* [with the word carer], we are *just mum*, are *just brother*, we are *just dad*… knock the word carer on the head. We don't need it!'. Matthew dis/avows definitions of 'carer' which fail to attend to the 'nested dependencies' and love in a family relationship in which he and his sister *exist* in the world together (Kittay 2019; Smith 2021; Ryan 2020). The importance of connection, mutuality of care and *just being a brother or sister* is shared by Daniel (a person with a learning disability) who supports his sister when she is 'stressing.' Emma (a person with a learning disability) described the care she gives in her group home to other people with learning disabilities, she told us that:

> 'I give my support workers time off by looking after my housemate. It's not easy but it's important. I give my carers a break'.

Emma's experience of caring prompted Cassie (parent carer) to say:

> 'My daughter is a bit like Emma – she's much better at keeping track of everything, reminding mum of what we have to do and need to do before etc. Sometimes when I'm flapping round, my daughter comes in and tells me to focus'.

People with learning disabilities and their family carers' accounts disrupt the simple binary of care-giver and carer-receiver. And yet, Bea (parent carer) explains that: 'I use the term because of the [social care] system' and 'we have to call ourselves carers in [health and social care] contexts'.

Kittay (2019) encourages us to attend to the contexts in which care is provided and this is one in which Bea feels she has to yield to the label 'carer' which is 'what the government calls us'. Matthew and Bea's complicated relationship with the term does not seem to relate to stigmatised identities, rather discomfort about how 'carer' is constructed in policy and practice. Carers and people with learning disabilities seem to be resisting the United Kingdom government's Care Act 2014 definition of a 'carer' as "an adult who provides or intends to provide care for another adult" which draws a clear boundary between the providers and the recipients of care (Her Majesty's Stationery Office (HMSO) 2014: 10). In their day-to-day lives, they are wrestling with issues of dependency, interdependency and autonomy leading them to dis/avow contemporary constructions of the category of 'carer' produced in the context of policy and service systems. When research identifies persistent disidentification with the term 'carer' by family carers as a barrier to seeking and accessing support services (Lloyd 2006; Guest and Corrigan 2018), there is an implicit assumption that carers should overcome this barrier (with professional support, perhaps). And yet, family carers are hoping to re-imagine policy and practice discourse in ways which more carefully reflect how people see themselves. In the blog post which followed the second Tea and Cake (Carers) group meeting, members offered this advice on the need to use and to refuse the terminology:

> 'We do have to call ourselves something. So, we are going to use the term 'family carer'. Each time we do we will explain that we are talking about people who love a person with a learning disability, who are also mum, dad, brother, sister, friend or neighbour.' (Smith et al. 2023)

In what follows, we use the term 'family carer' to honour their wishes. To be supported well, carers of adults with learning disabilities need those who support them also need to be mindful of the language, rather than imposing the language of practice and/or policy.

DIS/AVOWAL OF 'LEARNING DISABILITY'

Family carers and people with learning disabilities all used the term 'learning disability' to describe themselves or the person they care for. This is not surprising as learning disability remains the most commonly used term in the United Kingdom for people understood to have cognitive impairments (Cluley et al. 2018). However, as the conversations progressed in the meetings and workshops, the language of learning disability was less apparent. People spoke about 'my sister' or 'my lovely daughter'. It is possible to read these descriptions as the disavowal of the stigmatised category of learning disability (Zucker 2004), and yet, family carers and people with learning disabilities were happy to celebrate differences, and rather than disengaging with the category, they actively sought to disrupt pervasive ableist narratives

of learning disability as being in 'deficit' or 'lack'. Tamsin (parent carer), a member of the survey design group, described her daughter as 'never the problem' and sought out other people who embraced her daughter's difference and way of being in the world, although she felt that these spaces are 'few and far between'. Far from disavowing the category of learning disability, family carers stay with the trouble (Haraway 2016) of the category by asserting value in diversity, without Othering, and without erasing difference in ableist times (Cluley et al. 2018). While negative assumptions about 'learning disability' saturate day-to-day discourse and policy and practice, family carers and people with learning disabilities are challenging those assumptions and they require those who support them to do the same, that is, to question their own assumptions about the use of the language of learning disability and to work with people with learning disabilities and family members to disrupt the perpetuation of ableist narratives.

DISAVOWAL OF 'MENTAL HEALTH'

The term 'mental health' was also a contentious one for family carers. Tamsin (parent carer) began by disidentifying herself from the assumption that family carers of adults with learning disabilities experience mental distress. Tamsin said:

> 'One of the first things when I think about mental health and parent carers of a young adult with learning disabilities is firstly that there is an assumption to start with that there may be mental health challenges. I have never been on antidepressants, never been through therapy.'

Once more, social identity theorists might read Tamsin's disavowal of the status of 'mental health service user' as disidentification with a stigmatising category (Zucker 2004). A Mad Studies reading might see this disidentification with 'mental illness' as being underpinned by sanist myths and fears or being seen as 'different' and 'less than' other people; 'dangerous and frightening' or 'incompetent' (Perlin 1992: 45–46). But Tamsin goes on to explain that she sees the assumption that family carers of adults with learning disabilities have 'mental health issues' as driven by the ableist assumption that the person they care for is *the inevitable* cause of mental health issues. Crucially, Tamsin described the perpetuation of this assumption as a threat to her mental health, as is the failure of others to recognise the caring for her daughter brings her. Grace (sibling carer) also talks about the joy caring brings to her, the pleasure of going to the beach or the cinema with her sister when she goes home for a visit. Amir (sibling carer) described how happy it made him to see his sibling happy.

Deanna (parent carer), on the other hand, introduced herself by clearly identifying herself as someone who experiences mental health difficulties and a user of mental health services. She described her difficulties as feeling like a 'breakdown': 'I disengage, I don't respond, I ignore people'. However, she was clear about what she believed to be the cause of her mental distress offering a resounding rejection of the biomedical model of mental health. She described being 're-traumatised every single day' by her engagement with services systems that were supposed to help her and her daughter.

Deanna was also troubled by the dominance of biomedical models of mental illness (Rose 1998) in her life. She rejected what she described as the 'label of depression' which she said was:

> 'Unhelpful, as it's [something] being done to me, having to be on the roundabout all the time. Sometimes you just have to stay on the roundabout for hours. Always on the roundabout'.

In describing depression as something 'done to her', Deanna emphasises the social causes of mental distress (Beresford and Russo 2016).

In terms of mental health support, carers were clear about what would and would not help their mental health and recognised that 'standard approaches' to maintaining and sustaining mental health would not necessarily work for 'busy family carers'. As Florence (parent carer) said, 'aromatherapy vouchers' were not going to 'do it' for her and that this was a 'short term fix for a long-term problem'. Crucially, there were things that family carers believed would help their mental wellbeing. The first, not surprisingly, was that family carers felt happy when the person they cared for was happy. Caitlin (parent carer) said:

'The little things bring me joy, if I read [in the communication diary from her supported living home] that my daughter has gone out that week – she doesn't go out much – that brings me joy'.

In their first blog post, family carers agreed that 'caring' in and of itself 'gives me joy' (Smith et al. 2023), countering dominant narratives of caring as always and only a threat to mental health and wellbeing causing 'burnout' over time (Lindgren 1990). Family carers' dis/avowal of mental health services and support unsettles dominant narratives about the causes of family carers mental distress. Crucially, it also reveals the ways in which mental health services and support need to develop by policy makers, who commission and deliver health and social care services, *with* family carers in order to honour family carers' experiences and understandings of what causes and what mitigates against mental distress in their lives, rather than impose their own assumptions on the causes of mental distress.

DIS/LOCATIONS AND DIS/TEMPORALITIES OF CARE

Milligan and Wile (2010: 740) argue that analysis of landscapes of care must include an exploration of places in which care takes place as well as the 'past experiences and future expectations; the various temporal rhythms and routines of care'. Family carers were mindful of the changing nature of their caring roles across time and across spaces, aware that their experiences are constructed as out of place and out of time with 'normative' life course trajectories caring for longer and in different ways from other people. And so we explore the disruptive potential of exploring the dis/locations and dis/temporalities of care, embracing theories of ableism and sanism.

Time and place are entangled in experiences of care as Bea (parent carer) describes caring for an adult with a learning disability as 'exponentially harder' than caring for a disabled child, even if the person is 'living independently'. Bea spends two weeks each month living in a hotel and has done so for two decades so she can be close enough to support her son and his partner. Time haunts the lives of carers as they worry constantly about the future. Elspeth (parent carer) worries about there being a medical mistake which could have catastrophic implications for her daughter's mental health. She lives with the uncertainty of losing crucial Independent Health funding for her daughter and the loss of nursing support. She lacks trust in the care offered by residential college or supported living. Caitlin (parent carer) describes her fears for the future:

> 'My fears are that I don't have anyone to take over when I die so it will be the state. That is the most God-awful thing I can imagine. The stuff of nightmares, I can't go there. I can't explain it to my daughter, she doesn't understand as she has no reference for death. That's awful, that one day I won't come to her anymore'.

People with learning disabilities told us that they worry about the future too. Devi (a person with a learning disability) worries that her support staff will leave, it's happened before and she misses them when they go. Daniel (a person with a learning disability) is worried about living in supported living (a small group home for people with learning disabilities supported by care workers) away from his family in the future. He has a friend who currently lives in a supported living home; he says that where she lives 'sounds like a prison'.

The dis/locations of care and dis/temporalities of care, whether from near or afar and whether present or future, cause family carers distress. There are clear messages for policy makers who commission and deliver health and social care services – they must pay attention to the dis/locations and dis/temporalities of care if they are to offer people with learning disabilities and family carers the support in the present that would mean that they have no longer have a reason to fear what lies ahead.

DIS/POLITICAL LOVE AND THE DIS/ABILITY COMMONS

'We carry more, we do more that is stressful, but we do it because we love' (Tamsin).

Fearless, fierce dis/political love (Smith 2021) fills and fuels carers' lives and their caring relationships. Carers often describe the joy caring brings them and Matthew described the joy of 'seeing the person you love doing something they love is joyful'. Grace loves 'going to the

cinema or beach with her sister'. Emma (a person with a learning disability) shares that joy as she says she 'adores her sister, her family and her friends' and that: 'love is just a really good gift we've created, we should just spread it about'.

Dis/political love powers caring relationships, and also fuels family carers' relationships with one another as Tamsin (parent carer) goes on to explain:

> 'The fact that we have the experience of this [love] compels us to support, protect other people who are experiencing what we can identify with. [It is about] knowing the urgency at which friendships may be required and the willingness and response to these moments and how much these relationships mean. Holding each other, really holding each other for support'.

However, Tamsin (parent carer) also offers a word of caution:

> 'Support groups and the assumption that support groups are always supportive – they are not'.

Fierce love does not always lead to collective action and responsibility in these spaces, which can also be shaped by neoliberal-ableist and sanist demands.

And yet, what is clear is that the absence of love in the literature (Smith et al. under review) is startling when the threads of love are woven through the lives of family carers and people with learning disabilities (Smith 2021). Dis/political love matters for caring relationships and caring communities, it fuels collective responsibility and the dis/ability commons in resisting ableist and sanist assumptions and demands. Any consideration, in research or in practice, of the lives of family carers and people with learning disabilities which fails to centre love is, fundamentally, a failure to engage with the experiences of family carers and people with learning disabilities.

CONCLUSION

We began with the aim of thinking about the cultural politics of care with and through the frame of critiques of ableism and sanism, thinking with family carers and people with learning disabilities. We sought to critique and unsettle dominant narratives of care by drawing in and on theories of ableism and sanism as a way to develop a more collective and expansive cultural politics of care, in solidarity with carers and with adults with learning disabilities. We conclude by reflecting on how our analysis might shape the policies and practices of care.

We began with a call to remain sensitive to the ongoing ontological assumptions and repercussions of the words we use in policy and in practice (Smith et al. under review). Throughout the analysis 'learning disability', 'carer', and 'mental health', family carers and people with learning disabilities use and refuse these terms as they stay with the trouble of the categories by insisting on the value of diversity, resisting othering and holding onto the disruptive potential of difference in ableist times (Cluley et al. 2018). Responsive and enabling mental health services need to honour families' complex engagement with the categories that shape policy, practice and lives by being sensitive to their own ontological assumptions and the effects of perpetuating deficit driven language in contexts of caring relationships.

Many family carers' dis/avow dominant global North models which frame responses to mental distress in medicalised and individualistic terms, as they describe the way they experience trauma as 'something done to them' in and by services (Runswick-Cole et al. in press). Policy makers and practitioners need to stay with the trouble of their own (ableist and sanist) assumptions to better understand the causes of mental distress and how they can support people in distress, which move beyond individualised models of distress.

Services and support must pay attention to the dis/locations of care and dis/temporalities of care in families lives if they are to offer people with learning disabilities and their carers timely and sensitive support that ameliorates fear of the future. Crucially, researchers, policy makers and practitioners need to recognise and fuel the power of dis/political love in the lives of people with learning disabilities and family carers by allying with these communities (Finkelstein 1999). After all, any research, or offer of services and support, that fails to centre love and kindness fails family carers and people with learning disabilities.

DATA ACCESSIBILITY STATEMENT

Qualitative data relating to the Tea and Cake Group will be made openly available via ORDA (University of Sheffield), and qualitative data relating to the survey design workshops will be made openly available through E-Space (Manchester Metropolitan University) when the project ends in November 2024.

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The additional file for this article can be found as follows:

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