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Sticky Categories and Their Negative Consequences: People with Learning Disabilities and 'Behaviours that Challenge Others'

RESEARCH

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ABSTRACT

'Behaviours that challenge others' are attributed to 20% of people with learning disabilities. These behaviours are not a diagnosis, it is something people are labelled with. We conducted qualitative interviews with social care staff in the UK within four models of care: independent supported living, residential nursing home, Shared Lives, and living with family and attending a day opportunities centre. We examine how the category of 'behaviours that challenge others' is produced, applied, and contested in adult social care settings. We demonstrate its stickiness and discuss its stigmatising consequences. How behaviours are understood, felt, and talked about matters for the support people with learning disabilities receive and maps onto their consequent inclusion or exclusion from society. We point out the harms the category carries for people who receive it and argue that it should be abandoned.

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INTRODUCTION

Over one million adults with learning disabilities live in the United Kingdom (UK), representing over 2% of the total adult population (Mencap 2021). 'Behaviours that challenge others' (or 'challenging behaviour') are attributed to 20% of adults with learning disabilities (Bowring et al. 2017; Lundqvist 2013). People with learning disabilities who are categorized as having 'behaviours that challenge others' comprise a diverse group, including those with mild learning disabilities, epilepsy, mental ill health, severe and multiple learning disabilities, autistic people, those who injure themselves, or those who enter the criminal justice system (DH, 2007; NICE, 2018a; NHS, 2022). The term 'challenging behaviour' was adopted from the US, where it was introduced 'to transfer the demands for change from the individual with severe behaviour problems to the organisation around them' (Royal College of Psychiatrists 2007: 13).

'Behaviours that challenge others' is not a diagnosis (NICE 2015). It is a category that does not equate to a nuanced understanding of the behaviour, the person said to be displaying it, or their background, and might work to obscure these. This is because it can function as a catch-all phrase for things people might do that others find difficult to understand, threatening, or uncomfortable. We argue the category also carries an affective charge that deserves critical examination, and we ask what do the emotions *do* (Ahmed 2004)?

The category has been theorised as inherently relational and socially constructed (DH 2007; Royal College of Psychiatrists 2007) and it is recognised that people so categorized 'are often marginalised, stigmatised, disempowered and excluded from mainstream society' (Royal College of Psychiatrists 2007: 12). It is further acknowledged that 'behaviours that challenge others' can be a product of environmental factors (e.g., housing quality, service organisation and commissioning processes); and of individual characteristics (e.g., sensory disabilities or mental ill health, early onset dementia, traumatic history, bereavement and the onset of pain) (DH 2007; Norfolk Safeguarding Adults Board 2021; Young & Garrard 2016). These behaviours have also been understood functionally as a form of communication or stimulant of senses (NICE 2015).

Some environments, such as hospital settings (NICE 2015: 5), can increase the likelihood of these behaviours due to boredom, anxiety or pain (Royal College of Psychiatrists et al. 2007). It is within this context that we also ask whether we can uncritically accept categorising a behaviour that is a response to neglect or abuse as 'challenging' and what are the ethical consequences of doing so?

There have been calls to abandon the label alongside recognition of power inequalities underpinning relationships between people with learning disabilities and service providers (Oakes 2012). Cultural historians point to the inherent instability of categories applied to people over time, arguing that the 'presentism' that characterises recent scholarship in the field of 'learning disability' weakens the necessary critiques of current practice (Goodey 2001). The medical rootedness of much historiography has detracted attention away from long-running tropes such as 'the demonic idiot', which are used to reinforce 'a category of people against whom we rational modern (and post-modern) folk can identify ourselves, to affirm our intelligence and to assert our claims to respect and justice' (McDonagh 2008: 2). This serves to legitimize current categorizing and service practices, despite empirical evidence that demonstrates the impact of categories on the emotional responses and causal attributions made by care staff regarding so called 'challenging behaviour' (Gifford and Knott 2016). Such categories are therefore historically, culturally and socially contingent, and it is incumbent upon academics, practitioners and policy-makers to approach them critically and reflexively, attending to and contesting the ways in which they perpetuate long-term histories of discrimination, othering, abuse and inequities (Jarrett and Tilley, 2022; McClimens 2007; Oakes 2012; Tarvainen 2019) while considering the politics of emotion that reflect, and also sustain and reinforce them.

KNOWN HARMS

People with learning disabilities have poorer physical and mental health outcomes than the general population (Emerson et al. 2012; McMahon & Hatton 2021) and face exclusion and discrimination (Chatzitheochari et al. 2016; Coleman et al. 2013). The category of 'challenging behaviour' potentially adds another layer of disadvantage through, for example, increased risk of diagnostic overshadowing where medical symptoms are wrongly attributed to the learning disability (Heslop et al. 2013; Michael & Richardson 2008).

In the UK, the uncovering of abuse at Winterbourne View in 2011 (and in subsequent settings since) shone a spotlight on support for people with learning disabilities and autistic people, particularly in inpatient settings (Department of Health, 2012b). Notably, 'challenging behaviour' was found to be the most consistent 'characteristic' associated with the use of restraint and restrictive interventions (Fitton and Jones 2020). The description of a person as having 'challenging behaviour' is a key predictor of longer inpatient stay (Ince et al. 2022).

This points to direct harms associated with the category. Further, once a person is categorised as having 'behaviours that challenge others', it becomes part of their 'unauthorised biography' (Haydon-Laurelut and Nunkoosing 2016) or 'case history' (Gillman et al. 1997) and lives on in notes, reports and referrals (Haydon-Laurelut & Nunkoosing 2016: 146).

Whilst UK policy and guidance since the 1990s stresses the socially constructed nature of 'challenging behaviour', the term is still used (DH 2007) in the administration of commissioning, provision and funding. This has practical and material implications for people's opportunities, care and support. Despite evidence that people categorised as having 'behaviour that challenges others' can be effectively supported within their local community (Care Quality Commission 2021; National Development Team for Inclusion, 2010; Poll et al. 2006), people continue to be moved away to receive support in specialist out-of-area inpatient settings that echo the dehumanising institutions that dominated the twentieth century (Emerson et al. 2009).

People so categorised remain at heightened risk of living for long periods in inpatient settings and/or being placed in the care of 'specialist' providers away from their families and communities (Emerson et al. 2009; Ince et al. 2022; Slevin et al. 2008). The growing in-patient healthcare economy may go some way to explain how and why this issue has become seemingly intractable. People have been turned into commodities for private sector hospitals by healthcare entrepreneurs and well-established commissioning practices (Brown et al. 2017). Recent reports again highlight the continued failure to invest in the right support, with more urgent recommendations for improved support to people categorised as being 'challenging' (CQC 2020; Norfolk Safeguarding Adults Board 2021).

LABELS, FEELINGS, ASSOCIATIONS, AND STICKINESS – THEORETICAL CONSIDERATIONS

Labeling theory suggests that labels lead to stigma, through changing how a group is perceived by others and supporting stratification (Haft et al. 2023). According to Link and Phelan (2001: 383), stigma 'exists when elements of *labeling*, stereotyping, separating, status loss, and discrimination co-occur in a power situation that allows these processes to unfold' (emphasis added). The acceptance of categories as valid and important differences is described by the labeling element of stigma (Link and Phelan 2001). Here, we attend to how this 'labeling' aspect of stigma interacts with its other mechanisms in the category of 'behaviours that challenge others'.

We explore how the identifying and recording of these behaviours translates into the categorising of people and becomes shorthand for who they are. This is in line with labelling theory's postulate that, 'culturally given categories provide people with a means of making shorthand decisions that free them to attend to other matters' (Link and Phelan 2001: 369). This freedom, however, is not evenly distributed, and is enmeshed in a particular politics of emotion that we unpack in this paper.

Critical disability studies scholars have called for attention to emotions in how we think about disability (Reeve 2002; Thomas, 2004). Ability and disability co-constitute each other at the level of human relationships and interactions, and the emotions and emotional work involved in these processes have been examined (Goodley, Liddiard, and Runswick-Cole 2018; Liddiard, 2014; Sanmiquel-Molinero & Pujol-Tarrés 2020). Attention has been drawn to the burdens of psycho-emotional disablism, as a relational form of disablism experienced by disabled people in their interactions with, albeit not exclusively, their non-disabled peers (Liddiard, 2014; Reeve, 2002; Thomas, 1999). Emotions and affective (dis)attachments matter because they have material consequences that delineate and restrict disabled people's lives and claims to citizenship and humanity (Hughes 2015). Ahmed's (2004; 2004a; 2004b) work on affect is a helpful entry point into theorizing the work of emotions that happens when the category is invoked, attributed, and repeated. For Ahmed

> How we feel about another – or a group of others – is not simply a matter of individual impressions, or impressions that are created anew in the present. Rather, feelings rehearse associations that are already in place, in the way in which they 'read' the proximity of others, at the same time as they establish the 'truth' of the reading. The impressions we have of others, and the impressions left by others are shaped by histories that stick (2004a: 39).

Emotions are not private, rather, they 'circulate between bodies and signs' producing meanings and creating 'the surfaces or boundaries of bodies and worlds' (Ahmed 2004b: 117); thus, affect is always *distributed* (Wetherell 2015). We propose the category—and the labeling process behind it—should be understood within an ableist (Campbell 2009) distribution of affect and politics of emotion; one that subordinates the experiences of people with learning disabilities through establishing the 'truth' of the reading as external and mediated through the emotions of people without learning disabilities. 'Behaviours that challenge others' (and synonyms of the category) are inherently relational but also reflect and reproduce existing power imbalances. We suggest their stickiness rehearses and reinforces the ableist politics of emotion that positions people with learning disabilities as 'less human' (Goodley 2021) and at times as monstrous. The category is a product of this politics, one that repeats its rehearsed, sticky associations, making the reading of the proximity of people with learning disabilities in the present a result of histories marked by dehumanization. The method of categorizing people through labels also makes them more susceptible to what McClimens has described as 'reauthoring', with collective histories 'presented in a way that condones or even justifies their current situation' (2007: 259). In approaching it from this angle, we contribute to work that shifts the gaze away from disability to 'a more nuanced exploration of epistemologies and ontologies of ableism' (Campbell 2009: 3).

METHODS

This paper is based on interview data from an ethnographic study conducted as part of the Growing Older Planning Ahead (GOPA) project, which aimed to improve support for people with learning disabilities aged 40+ and their family carers. The ethnography was approved by the London-Camden and Kings Cross Research Ethics Committee (reference 12/LO/0062, obtained 1st February 2021)). The ethnography was conducted within four different models of care: independent supported living (4 sites: ISL A-D), residential nursing home (1 site: RNH), Shared Lives (2 sites: SL A-B) and living with family and attending day opportunities centre (1 site: DOP); all sites were identified as exemplary earlier in the project (Ryan et al. 2024).

The ethnography included observations by academic researchers and co-researchers (people with learning disabilities and family carers), interviews with people with learning disabilities, family members, support staff, managers, and commissioners. Researchers spent 12–25 days including some weekends and evenings at each of the four models of care. Co-researchers were present for around 30% of visits. The approach was to spend time with people being supported which included shopping, day centre sessions, attending dance, art and drama classes sharing a Friday night takeaway, sitting in the garden, going for walks, cooking, and watching television.

Seventy-one interviews were conducted with: support workers and local staff (n26); commissioners and service managers (n15); family carers and family members (n17); and people with learning disabilities (n13). Project information was shared in each site and with relevant commissioners and family members. Interviews were arranged via email contact with the research team or invitations during site visits. In this paper we focus on the perspectives of the first two groups, which for ease we refer to as 'staff'. Informed consent was obtained from all participants.

The interviews covered background of the interviewee, experience with the service, knowledge, experience, and understandings of 'behaviours that challenge others', and planning for older age. Interviews were recorded and transcribed verbatim by a professional transcription service. Data analysis and interpretation was done iteratively and involved participatory analysis.

Transcripts were openly coded thematically (Braun & Clarke 2006), with data constantly compared and coded independently by first author and another researcher. Initial codes were grouped under larger categories ('definitions and concepts of BTCO', 'responses to BTCO', 'perceived causes of BTCO'), alongside narrower categories ('BTCO and Covid', 'Dementia and BTCO' or 'Economic Aspects of BTCO'). The data was then analysed more conceptually, which allowed us to identify the key themes.

CO-ANALYSIS

Participation in analysis is often neglected even in co-produced research with people with learning disabilities, yet it is an important part of research (Nind 2011). Co-production was integral to the research design (see Mikulak et al. 2022; Ryan et al. 2024) and we worked together to develop new and innovative ways to involve team members with learning disabilities, DW and PB (a co-researcher and a co-applicant on the project) in the analysis. Building on previous experiences, we sought to create spaces to facilitate the production of 'entangled knowledge', which attended to the sensitivities, challenges and opportunities of collaborative meaning-making (Tilley et al. 2021).

We randomly selected three interviews and held two analysis workshops where we cut the respective audio sections from the interview recordings and presented the audio files and corresponding transcripts. Before the workshops PB, DW and LD met to read through and discuss the data, allowing initial reflections to be captured and shared. In workshop 1, the audio sections were played in full followed by playback of brief, 20–40 second sections. We discussed what PB and DW identified as the main points of each section.

To introduce further robustness, in workshop 2, we used audio and text extracts from data coded by the research team and compared the two sets of codes. Workshop sessions were audio recorded and transcribed to add to the previously coded data. This process generated a micro examination of data sections and discussion around how much 'fuller' the co-researchers found the audio extracts in contrast to text alone, the importance of not labelling people and of recognising the use of facial expressions and body language as forms of communication. Doing analysis together, rather than excluding team members from the process and opportunity to develop qualitative data analysis experience, reflected the co-production values underpinning the research. In practice, it created a unique space and time for further thinking about and discussing data and a shared exploration of meaning-making.

The GOPA project was funded in response to a specific call for research that focused on experiences of people with learning disabilities and 'behaviours that challenge others'. Epistemologically, we have thus found ourselves in what Gunaratnam (2003) has referred to as a 'treacherous bind'. Setting out to study the experience of people with learning disabilities through the lens of this category, our research risked further reification of the category and, by extension, becoming complicit in the harm it causes. Such complicity, however unintended, poses an ethical challenge for research teams.

We began to address this at the project start when permission was sought from the funder to change the term in the funded project title and protocol from 'challenging behaviours' to 'behaviours that challenge others', acknowledging the relational and socially constructed nature of the concept. The term was discussed in the interviews and mention of it during ethnographic observations was noted and discussed among the research team. Whilst we may not have initially set out to deconstruct the category, our research has led us to a critical place where we now seek to expose it as stigmatising and harmful, and where we are interested in examining the experiences of it being applied as a social category in an uneven power terrain.

'*EVERYBODY HAS TO BE SEEING THE SAME THING*': STICKY FEELINGS, LABELS AND POWER

How adult social care staff define, understand, feel, and what associations are rehearsed in these emotions about people they support and their behaviours, matters. If naming emotions involves different orientations towards objects they construct (Ahmed, 2004, p. 14), the way people's behaviours, their origins and functions are understood can foster acceptance of difference and affinity or can position the person as 'other' to be managed, contained, or as a problem. In its most extreme form, this process denies people with learning disabilities their humanity. In this section we explore staff understandings of the category and the consequences for people of being so categorised.

FUZZY DEFINITIONS AND NORMS

In discussing 'behaviours that challenge others', participants described different actions and/or behaviours including swearing, spitting, running off, shouting, being physically aggressive, being non-compliant, self-harming, getting undressed in public, or standing very close:

> He [person with learning disability] never left your side, he wanted to know everything you were doing, never watched the TV, wouldn't do anything on his own, had no hobbies. That would be very challenging to me. Classed as challenging behaviour (Carer, SL A).
>
> **I**: Can you explain what you understand as behaviours that are challenging to others?
>
> **R**: In all the various settings where I support, we have what they call low level challenges. And that could just be *general presentation* of spitting, biting, kicking or even non-compliance around personal care... So, then the extreme behaviours is somebody that maybe dysregulated that will have emotional issues and again that can't express why because of communication difficulties so they express it in their behaviours (Manager 1, RNH; emphasis added).

Some definitions offered a sense of reification conveying that the category is a 'thing' that exists with 'traditional' (medical/pseudo-diagnostic) manifestations (also present in the above quote, signalled by the phrase 'general presentation')

> So even though he [person with learning disability] might not do one of those things like shouting or screaming or being verbally aggressive or physically aggressive or self-harming, or *any of the other traditional ones*, doesn't mean he's not feeling things that might make him want to do that. Because he can't tell us the TV's on and the stereo's on and the blender's on at the same time, and that's a bit too much sensory overload for him (Local staff member 1, ISL B; emphasis added).

The acceptance of labels as both objective and meaningful is an indicator of stigma (Link and Phelan 2001). Moreover, in these definitions, we can sense the sociality of emotions that as Ahmed postulates, accumulate over time, 'as a form of affective value' (Ahmed 2004: 11) becoming 'traditional', 'general presentations' that widen the distance between the subject and the object. This in turn maps onto how emotions are bound up with sustaining social hierarchies, which Ahmed reminds us, are both intractable and enduring (2004: 12).

When defining 'behaviours that challenge others', participants referred to breaches of social norms, and how these transgressions could make others feel uncomfortable, anxious and/or threatened: "*I suppose it's behaviours that we don't see as socially acceptable, as the norm... I suppose behaviours that others find difficult*" (Commissioner 1, SL A). Such reading allows for attributing others (people with learning disabilities) as 'the source of our feelings' (Ahmed 2004: 1).

On the surface, the intra-subjective character of the label means that whether behaviour is categorised as challenging and to what degree comes down to the interpretation of the staff who witness and record it; a process that is mediated by their knowledge, experience, and personal values:

> And he [person with learning disability] did become quite physically aggressive with the Shared Lives carers, which, within your own home... I think he damaged furniture, he damaged their belongings. So when it's in your own home and they're things you bought yourself, that starts to cross your values, doesn't it, that "they're my possessions, they're things that I've worked for" (Commissioner 2, SL A).

> It's, you know, the fact that somebody else can, well I don't mind them spitting, you know, or I don't mind them regurgitating their food or anything, another person won't be tolerant of that. So, you know, it's accepting, not everybody can tolerate those things (Manager 2, RNH).

Yet, staff's knowledge, experience and values are embedded in affective histories in which being 'challenging' has come to be seen as a characteristic of some bodies and not others, and where any contact with the subject (person categorised as 'challenging') involves the subject as well as the collective histories that precede it (Ahmed 2004).

Definitions and thresholds of what is acceptable and to whom, and the feelings generated when these thresholds are crossed, appear to be flexible, subjective and interpersonal, but emotions are social and cultural practices (Ahmed 2004: 9) that reflect and sustain power relations. The latter point becomes visible when we consider how little control people whose experiences are being defined—people with learning disabilities—have over the process, a point we discuss next.

WRITING 'BEHAVIOURS THAT CHALLENGE OTHERS'

The emotions generated by an object become transformed and passed on as *knowledge* about the object (Ahmed 2004). Staff who name, record, and keep track of the behaviour are ultimately in charge of the labelling process. This requires an oversimplification to create categories (of behaviours) and groups (of people characterized as having them) (see also Link and Phelan 2001). It involves attempts to standardise something which, as demonstrated above, is seemingly subjective, yet contingent upon already familiar and established tropes that allow for the naming and categorisation of wide range of actions under one phrase.

> And following sort of in-depth analysis of that [person behaving in a way that is identified as challenging] asking people [staff] to complete charts and recordings about what happened before, what the behaviour is and… what was the consequence of that behaviour, is very specific, because everybody's got to see the same behaviour. To make any changes in support to that person *everybody has to be seeing the same thing* (Manager 2, RNH; emphasis added).

The threshold of what constitutes 'behaviours that challenge' depends on the staff witness, their colleagues and the employer's associated policies and guidance. The consensus of 'seeing the same thing'—and the necessary oversimplification of that agreement—happens within the accumulated effect of these shared knowledge and circumstances. This becomes particularly visible when the process of categorising invokes prejudices against people with learning disabilities as in need of external regulation and control:

> **R1:** Yeah. One of the individuals is, erm, I suppose… probably a little bit overtly *sexual*. Erm, incontinence that's potentially, we don't know yet, is that because it's medical, or is that "I'm unhappy so I'm gonna show you through incontinence"? So… sort of… wetting the bed, and just lying in it. Erm… I think most carers would, across a day, describe some behaviours that they found particularly challenging. If you think about [whispers to R2—inaudible] saying to the carer… what did he say?
>
> **R2:** "We're gonna F-ing kill you" [sic!] or summat.
>
> **R1:** Yeah, more, you know, verbal (Commissioners 1 & 2; SL A).

This extract rehearses a set of associations and feelings that have historically been attached to people with learning disabilities, where non-compliance, dysregulation and overt sexuality conjure feelings of urgency around containment and control. In the writing of people's unauthorised biographies, these 'truths' of the reading about how people behave and why, are ones that prevail, and stick, folded into support plans and notes (read by amongst others, the ethnographers) that follow the person. The stickiness, and the fact that within our cultural imaginary some figures get stuck together more readily than others—people with learning disabilities and 'challenging behaviours'/'behaviours that challenge'—as Ahmed (2004) argues, depend on past histories of association. It is these histories and not 'a matter of individual impressions, or impressions that are created anew in the present' (Ahmed 2004a: 39) that make it possible for certain affects to stick to certain bodies with greater ease, and to follow them around. These associations often work through concealment (a point we return to below) but also generate effects.

CONSEQUENCES OF THE STICKY LABEL

In the process, 'emotions become attributes of "collectives" which get constructed as "being" through "feeling"' (Ahmed 2004: 2). The resulting stickiness of the label means it can follow people with learning disabilities across their lives:

> I've always thought… that people who maybe were deemed to be very challenging as younger people, as they get older, they then become less frustrated, angry, whatever, and they're definitely not the same person, but then again, I'm not the person I was 20–30 years ago… So I think if you're growing older and you're still tagged with a label about something you did a long time ago, I really find that inexcusable really, but it's too easily done with clients (Manager 3, RNH).

Some participants critically reflected on the unfair distribution of the category, pointing at the double standard at work:

> I think if you look at society, we've all got behaviours that challenge. So I think it's really unfair to stick labels on our clients. And I struggle when we use those terms, especially when someone's in a lot of pain, to say their behaviour is challenging in some way…. Any one of us is capable of challenging behaviour. Any one of us. Anybody. If you are pushed and pushed and pushed and pushed enough… you'll have some challenging behaviour. No doubt. And so we're all the same. It's not a them and us (Manager 1, ISL C).

Staff also recognised the unfairness of denying people the right to be able to move beyond negatively attributed past actions. The category can continue to frame the person in a negative way regardless of the shape of their current lives, impacting their future possibilities as it allows staff (and others) to make assumptions about them or inappropriate decisions around their support.

> It can be negative sometimes because you pick up their case notes and it's full of all the things that they used to do but… You know, just because someone once upon a time threw the teapot or broke a window, should it define them 50–60 years on and it shouldn't (Manager 3, RNH).

Furthermore, some participants stressed how the category is used as a blanket explanatory term, a pseudo- or shorthand diagnosis, which can overshadow symptoms of developing or ongoing health problems:

> I know historically behaviours mask a lot of the reasons why clients don't get good healthcare, because people just put it down to the behaviour (Local staff member 1, RNH).
>
> And sometimes, it could be that, you know, it's just put down to that individual being that individual. You know, because quite often we hear "oh, that's just what they do". Or "that's what that person has done for a long time" (Manager, DOP).

There was also an acknowledgement that in social care, labels tend to follow a similar trajectory, from respectful to 'negative' as they get co-opted into the ableist health and social care culture and economy:

> We also know that label (of challenging behaviour) whatever it is, can get misinterpreted without explanation and understanding, so there's always a risk, I think, that people will perceive your intentions to be different or take the term and make it into another label, you know? So I've been in sort of social care quite a time and I've seen these sort of perceived more respectful labels turn into things over time… that are negative labels themselves (Local member of staff 2, ISL B).

Such co-optation becomes possible because the overall negative affective, accumulated value remains largely unchanged within these settings.

SOCIAL EXCLUSION, STIGMA, DENIAL OF VALUE AND HUMANITY

Labels lead to stigma (Haft et al. 2023; Shifrer 2013). Being categorised as having 'behaviours that challenge others' has long term consequences for people that extend beyond the epistemic injustice and difficulty in shedding the label. It others, devalues and pathologises them.

> it's a constant fight, isn't it? *If you have the label of having challenging behaviour, I think you also have the uphill struggle all the time to convince people that actually your life has potential* (Local member of staff 2, ISL B; emphasis added).

The negative emotional charge is rehearsed and repeated, increasing distance between *them* and *us*. At its most extreme, the affective disconnect becomes so strong that its logical extension is the denial of humanity:

> We went and worked alongside another company in a residential home, as we were kind of taking over from them. And they used to call him "the Monster". So that was what he was called, he was "the Monster". We were told to stay away from him, don't interact with him too much, just let him be, let him play his computer games all day. And then you went in and actually met him, and it was just this gentleman who had no-one to talk to. Because there was this label he had, and people became fearful of him. And I think that's what caused this kind of behaviour, was that no-one interacted with him, just on a kind of human level. So I think when we eventually took over completely and he moved to [city], we saw some small changes in the way he was with staff. We still had quite a lot of incidents, because he was still incredibly anxious around staff. But I think he actually enjoyed having that interaction with people (Local staff member, ISL C).

Emotions produce boundaries and surfaces that allow bodies to appear in the present (Ahmed 2004a), shaping our understandings of and responses to each other. In the affective politics of 'behaviours that challenge others' the boundaries of humanity are redrawn placing the lonely, anxious, and socially excluded person outside, where 'human level' interactions do not reach. Labelling people with the sticky label (and its synonyms) causes and perpetuates real harm, as evidenced above. When social labels signify 'a separation of "us" from "them"', they become a feature of the stigma process (Link & Phelan 2001: 370).

ALTERNATIVE NARRATIVES AND WAYS OF FEELING

Our research demonstrates it is possible to move away from the reifying and pathologising narrative of 'behaviours that challenge others'. One way is through resisting or reframing the label and dismissing it as grounded in an erroneous reading of reality—or, in labelling theory terms, refusing to accept it as objective and important (Link and Phelan 2001):

> we're changing… that label, well, initially internally, so we tend to call supposed challenging behaviours, behaviours of distress (Local staff member 2, ISL B).
>
> I hate it because previously it felt like it was something they were diagnosed with, and you can't diagnose behaviour [slight laugh]. But it was like a label. Someone had "autism and challenging behaviour"… And I hated that because… that's just their response to a situation. Change the situation, then you'll change the response. (Local staff member 1, ISL B).

Such reframing efforts are helpful; to reiterate, naming emotions 'involves different orientations towards objects they construct' (Ahmed 2004: 14). However, the extent to which adopting a new phrase (i.e. 'behaviours of distress') can recalibrate the affective politics in practice remains open to questioning.

Resisting can also be done through the removal of the label, through decoupling understandings of the person from formulaic definitions. At the root of this process is the commitment to and importance of *wanting* to know the person, which is reliant on recognising the person as someone of worth:

> Z can sometimes have outbursts and stuff like that, she can be labelled a little bit, like 'bad', like 'Z's oh yeah, Z, yeah, she's really badly behaved' and stuff, and that really irritates me actually, because *some people don't even know her* and they haven't even worked with her and they have just decided she's one kind of way, and actually we're all like this. We've all got different moods and different triggers and stuff and it's just about getting to know that person and how to keep things at baseline, instead of letting things escalate and *I think that you can only get good at that by knowing somebody*, so you get to know their character (Local staff member 3, ISL B).

Knowing the person extends to understanding they may get distressed or behave in a certain way because their needs are not being met.

> I think *it's just a person who is communicating in a world that doesn't want to listen*. I think that's kind of what it feels to me… their needs haven't been met. And they want to make their needs met, because usually it's just the basic needs. So if people aren't going to listen, then they have to get people to listen in other ways. Yeah, that's my kind of understanding of it really, at least from the people I've worked with. It was usually when they weren't being heard, which is when you would see them becoming quite distressed. Becoming maybe quite verbally aggressive, physically aggressive. And I think it would always be blamed on the person (Local staff member, ISL C).

The question of 'blame' is important; any blame resulting from a person's behaviour will be distributed unevenly, with people with learning disabilities carrying its burden. This is often in ways that obscure past injuries and harms inflicted on them; it is the past histories of association that work through concealment of harm (Ahmed 2004). Indeed, Ahmed (2004: 11) observes that some qualities seem to 'reside in the objects only through an erasure and history of their production and circulation'. Any reckoning with the label must therefore include an acknowledgement of complicity and how 'behaviours that challenge others' can be a response to experiences of trauma:

> Also what they learn and see in the hospital and the institutes, they say that by being angry or aggressive is the only way for a staff member to appear or to get attention or to be heard, so that's a very, learnt behaviours and the learnt challenging behaviours are a big part, along with the medication that you have to undo and unpick and then once you've got through that and that's very tough for the person and it's tough for the staff (Manager 2, ISL C).

This points to a circularity where the interventions and institutions set up to care for people who have been categorised as having behaviours that challenge, serve to generate and/or exacerbate the distress that results in those behaviours continuing, thus reinforcing the validity of the label for that person. And so it goes on, continuing to stick.

The proposed solution is an ethics of care based on personal connection and love for the person, which breaks the cycle of categorising and coercive control and acknowledges and values their humanity.

DISCUSSION

> Rather than seeing emotions as psychological dispositions, we need to consider how they work, in concrete and particular ways, to mediate the relationship between the psychic and the social, and between the individual and the collective (Ahmed 2004b: 119)

As Ahmed writes, emotions are not private, and in this paper, we have considered the work they do in the phrase 'behaviours that challenge others'. Our analysis highlights considerable variation in understanding, acceptance and use of the term 'behaviours that challenge others' across adult social care settings. Alongside oversimplistic categories, there is a lack of reflection and uncritical acceptance that this category is important and valid.

Many people engage in behaviours that challenge others, without the layers of censure, surveillance, and sometimes extreme responses, such as seclusion, restraint and medication that people with learning disabilities are subjected to. This is inherently unfair and harmful. Moreover, the label obscures more than it explains, for example, service failures, a lack of compliance to coercive norms, neglect and serious ill health. Ultimately, the category is a mechanism that reproduces and legitimises exclusion of people with learning disabilities and stigmatises them.

We acknowledge the efforts—both within our analysis and the wider literature—to contextualise the label as socially constructed; however, we propose a further step to dismiss it entirely. This is because its explanatory power is limited by its focus on how people without learning disabilities perceive, feel about, record and respond to a person *with* learning disabilities behaving in a particular way. This in turn is reflective of a certain sociality of emotions characterized by negative affective value accumulated through histories of disenfranchisement and abuse.

What follows is a catch-all phrase that harms people with learning disabilities whose way of responding to injustice, showing distress or simply communicating with the world is read as falling into this arbitrarily constructed category. Replacing the category with another will likely produce similar affective results and similar consequences for people with learning disabilities. Our insistence on getting rid of the label is in line with questioning by people with learning disabilities, families, practitioners, policy leaders and academics that have come before us (see for example Royal College of Psychiatrists et al. 2007).

The stickiness of the category extends beyond individual lives and into wider policy and service provision. This also begs the question of who benefits (both in terms of power and material resources) from sustaining the category bringing us back to the commodification of people and profit driven private providers (Brown 2017).

The politics of emotion at work in the often-uncritical process of labelling and reproducing the category today rehearse dehumanizing tropes that continue to stigmatize and devalue the experiences, feelings and knowledges of people with learning disabilities. The underlying fantasy of this politics is people with learning disabilities as docile subjects, complying with external demands and accepting the conditions, however unjust, under which they are placed. Given how the category is implicated in practices and enterprises that have negative impacts on people's lives, we cannot understand its continuous use as anything else than perpetuating harm.

Findings confirm that across care settings staff—past and present—control the documentation of people's behaviour. The subjects of such case records or histories do not appear to be treated as stakeholders in the recording process.

Our research evidenced health and social care practitioners who, like us, are actively calling for this category to be withdrawn from official and unofficial discourses of services and policy. They instead point to the need for greater attentiveness; replacing both the systematic and casual application of such labels with a deep and nuanced understanding of the person, their experiences, their life histories, the histories of other people with learning disabilities before them, and their ways of being and communicating in the world—creating a world that *does* want to listen.

Our research indicates the need for a renewed and urgent focus on the value of relationships, framed by reciprocity, creativity and compassion as well a need to reckon with familiar, stigmatising narratives that reinforce and obscure social hierarchies. It is time to ditch these categories.

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The authors have no competing interests to declare.

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